DOCUMENT RESUME

ED 417 540 EC 306 283

AUTHOR	Kaye, H. Stephen
TITLE	Disability Watch: The Status of People with Disabilities in the United States.
INSTITUTION	Disability Rights Advocates, Inc., Oakland, CA.; National Rehabilitation Information Center, Silver Spring, MD.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
ISBN	ISBN-0-9662355-0-9
PUB DATE	1997-00-00
NOTE	88p.; Introduction by Paul K. Longmore.
CONTRACT	H133B30002
AVAILABLE FROM	Volcano Press, Inc., P.O. Box 270, Volcano, CA 95689; toll-free phone: 800-879-9636; fax: 209-296-4995; e-mail: sales@volcanopress.com; World Wide Web: http://www.volcanopress.com ($14.95 per copy; $4.50 postage and handling for the first book and $1.50 for each additional book; California residents only add 7.25% sales tax).
PUB TYPE	Numerical/Quantitative Data (110) -- Reports - Evaluative (142)
EDRS PRICE	EDRS Price MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	*Accessibility (for Disabled); *Civil Rights Legislation; *Compliance (Legal); Demography; *Disabilities; Disability Discrimination; *Federal Legislation; Statistical Data
IDENTIFIERS	*Americans with Disabilities Act 1990

ABSTRACT

This report presents data in text and graphs on the situation of people with disabilities in the United States in the context of requirements of the Americans with Disabilities Act. An introduction identifies four reasons for the observed slow pace to compliance with disability-rights laws: (1) ignorance about what constitutes accessibility and reasonable accommodation and the achievability of these objectives; (2) serious defects in federal laws and policies which hamper social integration of Americans with disabilities; (3) failure by local authorities to enforce legal requirements for access and accommodations; and (4) continuing prejudice against people with disabilities. The sections following the introduction provide data concerning demographics, employment, social integration, barriers to independence, and transportation. Individual sections provide key points, an analysis of the data, illustrative graphs, and a comparison/contrast of myths and facts. Data sources are provided at the end of each section. A concluding section notes progress, but also outlines continuing needs, including job training, changes in employer attitudes, elimination of physical barriers in schools and businesses, an increase in the amount of accessible housing, an increase in accessible transportation, and a decrease in the segregation of people with disabilities, particularly the elderly and those with mental retardation or developmental disabilities. (DB)

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Disability Watch

The Status of People with Disabilities in the United States

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Disability Watch

The Status of People with Disabilities in the United States

A report by Disability Rights Advocates, Inc.
Statistical information provided by the Disability Statistics Center, University of California, San Francisco.

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This publication was produced for Disability Rights Advocates
by
Women and Children's Support Resources, a California nonprofit corporation.

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Library of Congress Catalog Card Number: 97-78302

ISBN: 0-9662355-0-9

To order additional copies of ***Disability Watch***, please send $14.95 for each copy. For book rate postage and handling, add $4.50 for the first book and $1.50 for each additional book. Priority mail rates available. California residents only add 7.25% sales tax.

Volcano Press, Inc. • P.O. Box 270 • Volcano, CA 95689

phone (800) 879-9636 • fax (209) 296-4995

Web address: http://www.volcanopress.com • E-mail: sales@volcanopress.com

Printed in the United States of America.

Disability Rights Advocates
would like to thank our staff and volunteers for their support and wishes to express sincere gratitude for the contributions that made this publication possible, including:

The Peter Blanck Family Fund
De Goff and Sherman, Attorneys at Law
The Dole Foundation
Marni Goldman
LD Access Foundation
Nordstrom, Inc.
Anne E. Schneider

The Disability Statistics Center
at the University of California, San Francisco is funded by:

The National Institute on Disability and Rehabilitation Research,
U.S. Department of Education, under grant H133B30002.

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"Not OK." These were some of the first words my son learned to speak.

When we encountered barriers such as an intersection with no curb-cut, so that I had to roll through the street in the traffic with him on my lap, or when I could not get into a store or restaurant, he would say, *"Not OK."* It was something even a two-year old could understand.

Our society has made great strides in overcoming a history of prejudice, fear, and exclusion concerning people with disabilities. For centuries, a person with a disability was an object of fear or pity. People with disabilities were marginalized and segregated, often kept in institutions or hidden at home. It was assumed as a fact of nature that people with significant disabilities could not be full participants in life, that we could not hold down regular jobs, raise families, or become leaders in our communities. Even Franklin D. Roosevelt, one of the most heroic figures of the twentieth century, had to hide his disability out of fear that he would not be considered capable of leadership if people knew he could not walk.

Today, these assumptions are under challenge in every area of life. Passage of the Americans with Disabilities Act signaled an historic awakening. The ADA affirmed that people with disabilities are no different from non-disabled persons in the things that matter most: our desire to be full participants in everyday life, our ability to contribute to the social and economic life of the nation when barriers are removed, and our basic human right to be given that opportunity.

Old stereotypes and attitudes do not die easily, however. All too often, people with disabilities are still marginalized and deprived of equal opportunities due to unnecessary barriers and fears. As this *Disability Watch* report shows, laws guaranteeing equal rights have not brought an end to discrimination against persons with disabilities in the areas of employment, education, housing, access to public accommodations, and social integration. As my son would say:

- *It's not OK that almost three-fourths of working-age Americans with significant disabilities, the vast majority of whom want to work, don't have jobs.*
- *It's not OK that 30% of people with such work disabilities live below the poverty line.*
- *It's not OK that large numbers of people with disabilities continue to live in dehumanizing institutions.*
- *It's not OK that barriers remain rampant in public accommodations and mass transit.*
- *It's not OK that people with various types of disabilities, such as mental disabilities, learning disabilities, and HIV/AIDS, continue to be subjected to blatant discrimination and archaic stereotypes.*

Passage of the ADA and other disability civil rights laws was not an end but a beginning. The struggle must continue in every arena to make the dream of equal opportunities for people with disabilities a reality. We owe this to every person with a disability. We owe this to our children.

Laurence W. Paradis
Executive Director
Disability Rights Advocates

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Introduction

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During the past generation, Americans with disabilities have pressed for equal access to U.S. society—to school, work, public transportation, and public places. Most observers regard passage of the Americans with Disabilities Act in 1990 as the high-water mark of that movement. Two-thirds of the disabled adults responding to one recent survey reported that since ADA their "quality of life" has improved. The evidence presented in this *Disability Watch* report does indicate important progress in some areas.

Yet many people with disabilities continue to endure economic deprivation and social marginalization. Depending on age and definition of disability, poverty rates among disabled people range anywhere from 50% to 300% higher than in the population at large, while a large percentage live on the meager financial aid supplied by federal income-maintenance programs. People with disabilities are also less likely to complete high school or college and far less likely to get jobs. The unemployment rate among those who report any form of disability is twice the national average. If they do obtain jobs, it is more likely to be part-time, and on average they will be paid 20% less than non-disabled workers.

They tend to be socially isolated too. Despite some improvement in accessibility, people with disabilities are still far less likely than non-disabled Americans to go to restaurants, movies, concerts, sporting events, churches, or stores. They are twice as likely to live alone. Those who grow up with disabilities tend to marry later, if they marry at all. Disabled women in particular marry and form families significantly less often than non-disabled women or even disabled men.

Social isolation and economic deprivation are not new among Americans with disabilities. They have long experienced these stark disadvantages. But the disturbing finding of this *Disability Watch* is that since the mid-1980's these conditions have improved modestly or

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not at all, and in some areas, such as earnings, things have actually gotten worse. The question is: why?

Different observers typically offer one of two differing answers. They focus either on the individual or on the environment. They ascribe the socioeconomic disadvantages suffered by disabled persons to their "impairments," or attribute them to the synergy of public policies, institutionalized societal practices, and the built environment. These competing explanations respectively express two contending paradigms of disability: a medical model and a sociopolitical model.

The medical model locates the problem of disability in the bodies of "afflicted" persons. By defining disability as a pathological medical condition, it inevitably individualizes the causes of socioeconomic disadvantage: impaired individuals cannot function appropriately within society. Some of the data drawn upon for *Disability Watch* are based on medical definitions of disability. That research defines disability as a limitation, due to a health problem or impairment, in performing "major activities," meaning the endeavors ordinarily "expected" of people in particular age groups. Thus, children are expected to attend school and to engage in play as their major activities. Working-age adults are expected to hold jobs outside the home or to keep house. Older adults are expected to manage their households and to care for themselves. By this yardstick, some 26.8 million Americans (10.3% of the total U.S. population) are defined as limited in their ability to perform the major activities expected of persons in their age group. Various studies also report that the most common form of "major activity limitation" is "work disability," a partial or total limitation in an individual's ability to perform a paid job. Such limitations reportedly affect 19 million working-age adults with disabilities. The trouble is that, as with all medical definitions of disability, these definitions of "work disability" and "major activity limitation" focus attention exclusively on individuals. The definitions implicitly assume that the limitation results from medical pathology and resides within individuals. These ways of measuring disability fail to measure the impact of external, societally created factors in limiting disabled persons' capacity to perform "expected" social roles.

In contrast, research based on a sociopolitical model of disability explicitly examines the architectural, socioeconomic, and policy environments within which people with disabilities must operate and that shape their experience of disability. Those sorts of studies, which provide the bulk of the data analyzed in *Disability Watch*, present markedly different explanations of the disadvantages suffered by many people with disabilities. The evidence gathered here offers a comprehensive picture of artificially created marginalization and deprivation.

One aim of this report is to assess the impact and effectiveness of the Americans with Disabilities Act. Itself based on a sociopolitical model of disability, the ADA, enacted in 1990, mandated conversion of the U.S. physical and social infrastructure to make it inclusive of

people with disabilities. Seven years later, ramps and blue wheelchair-access symbols and Braille markers seem to have sprouted everywhere. Increasingly, sign-language interpreters seem now always to interpret public events. Thus, the non-disabled public has the impression that society has been transformed and made accessible. Significant improvements have been made, but *Disability Watch* indicates that to a surprising extent U.S. society continues to restrict or exclude people with disabilities.

The problems begin with modes of transportation. Americans have long considered mobility a major issue, both a core value and, given the vast geography of the country, an inevitable public concern. They have come to regard freedom of movement as a basic right. Yet *Disability Watch* reports that Americans with many kinds of disabilities still often find their mobility rights restricted or denied.

Take for instance public transit. Although a majority of public buses now do have wheelchair lifts, those lifts are often broken and bus drivers often receive little training in how to operate them. Because the ADA requires public-transit agencies to include wheelchair lifts only when they buy new equipment, few cars on light-rail, rapid-rail, inter-city, and commuter-rail systems now accommodate wheelchair riders. And since the ADA orders full access only at newly built transit stations and at existing "key" stations, inaccessibility prevails in most places. The U.S. Department of Transportation considers a mere 700 stops nationwide as "key stations." It reports that nearly two-thirds of them are at least partially accessible to wheelchair and walker users, but that just a fifth are fully accessible to people with mobility or sensory impairments. But those figures overstate the effective accessibility of some transit systems. Both Atlanta's MARTA and the San Francisco Bay Area's BART profess to be fully wheelchair-accessible, yet disabled riders report that ticket vending machines and booths and turnstiles are often inaccessible and that elevators regularly break down. In New York City's subway system, a mere 28 of stations meet legal access requirements, while the rest of the 490 stations remain unusable. Around the U.S., all forms of public transit typically fail to provide the audible or visible information necessary for blind, deaf, or hard-of-hearing passengers to travel safely and effectively, even when such information is legally mandated. Thus, while many public-transit systems claim full accessibility, the vast majority of public-transit buses, cars, and stations still effectively exclude many passengers with disabilities.

When people with disabilities cannot use regular transit, ADA instructs local public-transit agencies to provide paratransit services. Three-fourths of those agencies reportedly offer such services in the form of "special" buses, vans, or taxis. But disability-rights activists condemn paratransit as separate and unequal, and with good reason. Eligibility procedures often make new applicants wait months. Service is frequently costly and therefore limited, with lift-equipped vans often charging $20 a ride and some subsidized taxi rides set at a maximum of $100 worth of travel a month. Paratransit is also commonly inflexible and inconvenient. Agencies require advance reservations of anywhere from 24 hours to as long as

two weeks—for each and every trip. As this report notes, it is clear that some local agencies see paratransit not as "an essential substitute for unusable public transit," but as a charity service for "special" trips such as doctor visits. Whatever the rationale, paratransit perpetuates the social marginalization of people with disabilities. Yet, because they have no other options, disabled passengers use paratransit heavily.

The inconveniences inherent in paratransit services and the pervasive inaccessibility of most public-transit systems have a profound impact on the lives of many Americans with disabilities. Those conditions contribute to their exclusion from community life and block them from gaining employment. In a 1994 survey, one out of four individuals with disabilities who were not working or working only part-time named the lack of affordable, convenient, accessible public transit as an important reason they could not obtain a job.

If public transit is still largely inaccessible, commercial modes of long-distance travel present major access problems as well. Intercity bus lines, led by industry pacesetter Greyhound, vigorously resisted any ADA requirement that they provide wheelchair access. Thus, commercial intercity bus travel still completely excludes wheelchair riders. Because of limited access to other modes of long-distance travel, people with mobility or visual impairments use airlines heavily, yet no law guarantees them the right to fly. The ADA overlooks airline travel altogether, and the Air Carrier Access Act of 1986, the federal law that supposedly ensures disabled Americans' right to fly commercial airlines, in fact contains no guarantee of equal access. This weak law allows airlines to treat access and accommodations for passengers with disabilities as an afterthought. *Disability Watch* recounts a litany of problems with boarding, seating, debarking, poorly trained personnel, and damage to wheelchairs and other equipment.

The obstacles impeding air travelers with disabilities are not just in the air. Because federal law mandates retrofitting terminals for complete access only when they are renovated, many major airports—Kennedy in New York, Midway in Chicago, Miami, Philadelphia, and Fort Myers—continue to have serious access problems. The ADA does cover airport shuttle services, but under much more lenient requirements than those governing public transit. No surprise then that many airports have no accessible shuttle buses at all. This forces wheelchair riders to pay for costly lift-equipped vans. Some airports do offer accessible shuttles, but these may operate more like paratransit systems than integrated services. For instance at Dallas/Fort Worth Airport, non-disabled travelers may simply board any waiting shuttle bus, but wheelchair users must reserve a ride on the system's single wheelchair-accessible van 24 hours in advance, or they can hire another lift-equipped van at four times the cost. At many airports, shuttle-bus drivers lack adequate training to operate wheelchair lifts and tie-downs, at times endangering their passengers.

Car rental agencies have restrictive policies and practices too. They may not have vehicles equipped with hand controls or may offer them only on bigger, more expensive cars. Rental outlets also often require lengthy advance notice. And some agencies refuse to rent vehicles to disabled individuals unless they can drive the car themselves. Departing from this pattern, several national chains, such as Avis and Alamo, recently agreed to change their

practices. These companies have commited to provide rental vehicles with hand controls on reasonable advance notice, will not charge extra for such vehicles, and will permit non-driving customers with disabilities to assume financial liability for rented cars driven by another person. Other national rental car companies, however, continue to discriminate.

At least people with mobility disabilities now have lots of places to park, or so many people assume. But in fact, a 1993 national survey by the U.S. General Accounting Office found even that assumption mistaken. People with disabilities reported that in many public lots the spaces designated wheelchair accessible are too narrow or on a slope that is too steep. They also said they often can find no place to park at all, because many public lots have fewer accessible spaces than the ADA requires. GAO investigators confirmed these complaints. While some 5% of Americans have "severe mobility limitations," ADA requires smaller lots (under 400 spaces) to make only 4% of their spaces accessible, mid-sized lots (400-1,000 spaces) to have 2% accessible, and large lots a mere 1% accessible. Yet, the GAO found that well over a third (38%) of parking lots they inspected had even fewer accessible spaces than the already inadequate number mandated by ADA. In addition, 57% of spaces and aisles were too narrow and 88% of the inspected lots lacked the required number of "van-accessible" spaces.

Then there are all those ramps the non-disabled public takes as evidence that public places have been made accessible, implicitly thinking of access as an issue only for people who ride wheelchairs. But once again, subjective public perceptions are mistaken. Many ramps are too steep or too narrow or lack a handrail or lead to a door that cannot be opened. And access obstacles in public buildings do not end at the tops of ramps. Some building entryways are linked to security systems that require voice communication or sight. Wheelchair riders frequently find store aisles too narrow or blocked, service counters too high, restaurant tables too low, and drinking fountains unusable. When theaters and lecture halls and other public venues do provide wheelchair-accessible spaces, they often segregate them from the rest of the seats, forcing wheelchair riders to sit apart from friends and colleagues.

Restricted access to information and communication in public buildings is another major problem. Most buildings lack enough signs indicating the location of accessible features or identifying rooms in Braille or raised-print. Programs such as museum brochures and transit schedules are often unavailable in large-print, Braille, or audiocassette or through staffers trained in sign language. Elevators usually lack either audible signals or Braille signs. Public telephones are often inaccessible. They are too high for wheelchair riders, lack signage appropriate for people with visual impairments, and lack text telephones for deaf people or phones with amplification for hard-of-hearing people. Businesses often do not have TDD numbers.

Inaccessibility in hotels remains a common problem too. The vast majority of U.S. hotels still have not instituted legally required access features. They do not supply devices to alert deaf guests of fire alarms, ringing phones, or someone knocking at the door. They fail to provide raised-print maps of hotel locations for visually impaired guests. They have too few rooms with wheelchair-accessible bathrooms.

One in four Americans with disabilities cites one or more of these various access obstacles as limiting their use of facilities that serve the general public.

If public buildings continue to have significant access problems, private housing remains pervasively exclusionary. A tiny fraction of U.S. houses and apartments are accessible or even readily adaptable for prospective residents with disabilities. One study cited in *Disability Watch* found that a mere "2.9% of Americans lived in homes with any kind of accessibility features," yet 29.2% of U.S. families included at least one member with a disability. The extraordinary shortage of accessible or adaptable housing makes the search for suitable housing a seemingly futile quest. It forces many families with newly disabled members, who are often elderly, to exclude the member with the disability, which often means putting that person in an institution. Yet, unlike businesses, private homeowners have no tax credit available to subsidize and encourage modifications to residential housing. In addition, while the Fair Housing Amendments Act of 1988 requires landlords to allow disabled tenants to make necessary alterations, it puts the burden of those changes exclusively on the tenants. The Act does mandate certain limited accessible and adaptable features in newly built multi-unit housing and prohibits disability-based discrimination in the rental or sale of most multi-unit apartment buildings and some single-family houses. But newspaper reports indicate that local authorities usually fail to enforce any of these provisions. Thus, this law is having only a very limited impact on the extreme shortage of accessible housing.

Perhaps the greatest progress toward the integration of people with disabilities has appeared in U.S. public schools. Americans have long viewed education as the key to economic opportunity and to full participation in society, yet for decades many states by law barred youngsters with specified disabilities from attending public schools. As of 1975 most children with disabilities in the U.S. either received no public education at all or were denied equal educational services. By the late-1990's, the impact of federal laws and the efforts of disability-rights advocates have produced significant changes.

Most children with disabilities now attend public schools. A growing proportion are mainstreamed. And a majority of teenagers with disabilities complete high school, which greatly improves their job prospects.

But "mainstreaming" also has its negative side. Public-school districts too often assume that "mainstreaming" or "full inclusion" is the most appropriate solution for all children with disabilities. In fact, that strategy is proving disastrous for deaf children. Placing them in mainstream classrooms denies them the opportunity to learn American Sign Language, inhibits their acquisition and development of skills in any language, and effectively isolates

them among hearing children. The Deaf community has vigorously opposed these ill-considered practices, but its cogent dissent has gone largely unheeded.

In addition, despite considerable progress toward integration of disabled students for whom mainstreaming is appropriate, many public schools still contain "formidable" physical barriers. Although no one gathers data nationally on accessibility in U.S. schools—a major deficiency that demands correction—a 1989 opinion survey did report that one-fifth of parents with children in special education and one-fifth of public-school educators rated access in their schools' physical facilities as only "fair" or "poor." Confirming these perceptions, a 1995 GAO study found that a majority of school districts needed to improve access and that in some large districts, such as Chicago and New Orleans, most school buildings were inaccessible. In addition, a court ruling against the Oakland, California public school system found "multiple, pervasive architectural barriers" in every one of its 100 schools. These conditions persist despite the flexibility of federal laws that require "overall access to programs and activities," rather than removal of all physical barriers in every building. The greatest problems occur in central-city school districts that have more limited financial resources, whereas wealthier suburban districts have made better progress toward accessibility. Even many wealthy school districts, however, have totally disregarded barrier removal requirements. Much work remains to be done in order to reach the goal of access to public education for all of America's children and youth.

Taken together, the data presented in *Disability Watch* show that, over seven years after passage of the ADA, U.S. society still often unfairly limits or excludes people with disabilities. The evidence here suggests four reasons for the slow pace of compliance with disability-rights laws and the continuing marginalization of Americans with disabilities.

First, there is still a great deal of ignorance about what constitutes accessibility and reasonable accommodation and the achievability of those objectives. Many business people and property owners are misinformed and therefore anxious and angry. In particular, they mistakenly believe access and accommodations are costly. In fact, incorporating accessibility in the design of new buildings increases construction costs by no more than 2%. Retrofitting for access can prove more expensive, but ADA requires such modifications only when buildings are being renovated or when they are "readily achievable" in existing buildings and would not cause "undue" financial hardship. Most of the time the price of barrier removal and installation of accessible features is relatively low. In 1993, small businesses spent an average of $3,327 on retrofitting for access, with individually-owned businesses spending even less, $2,535. And the federal government rebated 50% of these costs under the Disabled Access Tax Credit. The remaining expense should be more than reimbursed by the addition of new customers who have disabilities. Common fears about the price of job accommodations for employees with disabilities also overstate those costs. Nearly 70% of job accommodations cost $500 or less, with almost a fifth incurring

no expense at all because they entail merely the rearrangement of work spaces or work patterns. Further, many business people overlook that the expense of job accommodations is usually much less than the cost of training a replacement employee. So, concludes *Disability Watch*, complaints about the financial impact of accommodations and accessibility are greatly exaggerated and cannot be used as an excuse to evade compliance with the law. Besides, compliance now will avoid costly lawsuits later.

Most architects are also still uneducated about how to design for equal access. *Disability Watch* urges readers to note two innovative approaches: "adaptable design," a strategy that incorporates certain basic access features and allows for others to be added conveniently later as they are needed, and "universal design," a scheme that plans spaces and equipment so that everyone can use them.

Second, social integration of Americans with disabilities is slow because federal laws and policies contain serious defects. Some civil-rights statutes have weak enforcement provisions. For example, not only does the Air Carrier Access Act fail to guarantee travelers with disabilities equal access to airlines, but some court decisions have held that the act provides no injunctive relief in court, only meaningless administrative relief. And the ADA's requirements to make public transit accessible allow agencies as long as twenty years to comply. No wonder then that, as *Disability Watch* notes, "some transit districts have not even begun the ADA-mandated planning phase for improving accessibility, let alone made any actual improvements."

Other federal policies continue to promote dependency rather than productivity. The government spends forty times as much on social-welfare benefits as on vocational rehabilitation. Its regulations and practices also still deter many disabled people from seeking employment by penalizing them with the loss of essential assistance or health insurance if they go to work. In one survey, almost a third of working-age adults with disabilities said that that threat stood in the way of their taking a job. National policies could facilitate productivity by removing these work "disincentives." Policies could also foster competitive job skills among disabled individuals by subsidizing their acquisition of computer technology. In the midst of a technological revolution so often vaunted as liberating for people with disabilities, it is amazing that while one-tenth of disabled working-age adults say they would need adapted equipment to hold a job, only 1.3% actually own such equipment.

Federal policies also promote institutionalization rather than community integration. Not only is there no homeowner's tax credit to encourage accessibility in residential housing, but Medicaid funding favors nursing-home placement over enabling disabled people to live in their own homes. As a result, the number of institutionalized disabled Americans, the vast majority of them elderly, stands at an all-time high of 2.1 million.

In combination, these flaws in federal policies and laws effectively perpetuate the social segregation and economic deprivation of people with disabilities. Some policies actively promote marginalization. Other

statutes delay removal of physical and social barriers to integration.

Third, even when the legal requirements for access and accommodations have already gone into effect, compliance is dilatory because local authorities often fail to enforce them. For example, a current lawsuit by disability-rights activists charges San Francisco city building inspectors with routinely exempting new and remodeled construction from state accessibility codes. As a result, hundreds of buildings illegally exclude wheelchair riders. Similar problems occur when local public works departments neglect to remove barriers in streets and on sidewalks. Enforcement and compliance varies widely from community to community depending on three factors: the priorities of local public officials, the resources available to them, and the degree of activism by local disability communities. The last element is proving especially important.

In response to lax implementation and widespread violation of disability-rights laws, activists around the U.S. are increasingly filing civil suits to compel vigorous enforcement. For example, *Disability Watch* reports lawsuits against or settlements with the Days Inn hotel chain, Lone Star restaurants, United Artists Movie Theaters, Safeway Stores, Planet Hollywood restaurants, Bay Area Rapid Transit, Metropolitan Atlanta Rapid Transit, the San Diego municipal courts, and the operator of a parking-lot chain in San Diego. In all of these cases, the companies and agencies simply ignored the law, sometimes defiantly.

That conduct points to the fourth factor delaying integration of people with disabilities into American society: the refusal to comply with these various laws stems not just from ignorance, but also from prejudice. Around the U.S., people with disabilities report encountering prejudicial and discriminatory treatment. In some cities, bus drivers simply refuse to pick up passengers with visible disabilities. Airline employees are often uncooperative or unresponsive, and at times physically rough or humiliatingly rude. Working-age people with disabilities recount various forms of discrimination: they have been refused jobs, denied promotions, given less responsibility than non-disabled co-workers, or paid less than non-disabled colleagues doing similar work. In one survey, forty percent of disabled adults who were unemployed or working only part-time declared employer bias was a factor.

Yet despite the persistence of discrimination against disabled Americans and lax enforcement of the laws to protect their rights, U.S. society cannot avoid disability-related issues. One reason documented in *Disability Watch* is the steadily growing number of Americans with disabilities. Depending on definitions of disability, there are now at least 41 million people with significant disabilities in the United States. Disability occurs more frequently in lower-income groups and among racial minorities, but most of the numerical increase has resulted from the mounting size of the elderly population. Here again though, *Disability Watch* corrects some common

misconceptions. Most people with disabilities are not old. In fact, a majority (57.6%) are working-age, while more than one in ten are under age 18. And the most rapid rate of growth in the incidence of disability is occurring in those younger age groups. Among children and teens, much of the increase stems from the rising prevalence or more effective detection of asthma, emotional disabilities, mental retardation, and learning disabilities, while a growing proportion of young adults experience orthopedic, mental, and emotional disabilities. In addition, "disability" involves widely diverse conditions, with many of the more common, such as heart disease, back problems, arthritis, learning disabilities, and emotional disabilities, relatively hidden. Not only are Americans with disabilities a large and diverse population, the experience of disability is typical rather than rare. Nearly one-third of U.S. families have a member with a disability, and most families experience disability at some time. "Disability," this report concludes, "is a normal part of life . . ."

Thus, the number of people with disabilities continues to grow. Their presence in American society, their needs and interests, increasingly make themselves felt. And, more and more, disabled Americans are asserting their right to participate in U.S. society, in its schools, places of work, places of business, and community affairs. More and more, they are turning to legal and political activism to enforce those rights. As they become active, they are rejecting a medical model of disability and espousing a sociopolitical one. In the end, *Disability Watch* should bring readers to at least this one conclusion: disability issues will not go away because people with disabilities are not going away.

Demographics

By a fairly conservative estimate, 15% of Americans have disabilities, making this group the largest single minority in the United States. According to data from the 1994 National Health Interview Survey, 39.1 million U.S. household residents are limited in activity due to a chronic health condition or impairment.

Activity limitation is one of the principal ways of defining disability: A person is considered to have a disability if he or she has a chronic physical or mental health problem (a disease, disorder, or aftereffect of an injury that has lasted at least 3 months) or an impairment that restricts the ability to perform one or more activities. "Activities" can range in importance from eating to working at a job to riding a bicycle. The restriction can be total, rendering the person unable to perform the activity, or partial, proscribing the amount or kind of activity that can be performed.

Some 26.8 million Americans, or 10.3% of the population, are limited in their *major activity;* of these, 11.5 million people (4.6% of the population) are unable to perform their major activity. A person's major activity is age-dependent: attending school or engaging in play for children, working or keeping house for nonelderly adults, and managing the home and taking care of oneself for elderly persons.

Work limitation is the largest component of major activity limitation: 19 million working-age adults (11.6% of the population aged 18–69) are restricted in their ability to work at a job or business. More than half of this group—10.9 million people—report that they are unable to work.

Functional limitation provides a different dimension for measuring disability. Some 16.4% of the U.S. population aged 15 and above—33.2 million people—experience one or more limitations in physical function, according to 1994–95 data from the Survey of Income and Program Participation. This group is comprised of 8.3 million people who have difficulty seeing words and letters, 9.7 million who have trouble hearing normal conversation, 2.0 million with speech impairments, 16.0 million who have difficulty lifting or carrying a 10-pound object, 18.0 million who have trouble

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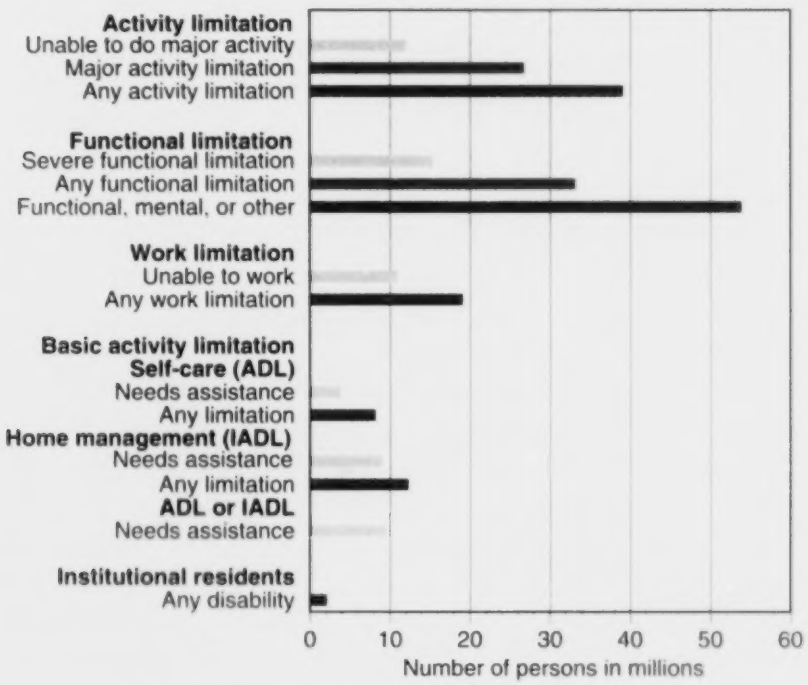
U.S. disability population by degree and type of limitation



Sources:
Activity limitation: 1994 National Health Interview Survey
Functional limitation: 1994–95 Survey of Income and Program Participation
Work limitation: 1992 National Health Interview Survey
Basic activity limitation: 1994–95 Survey of Income and Program Participation
Institutional residents: 1990 Census

climbing stairs without resting, and 18.4 million who have difficulty walking 3 city blocks.

These are relatively broad measures of functional ability: it is likely that many people who find it difficult to walk three blocks or who need to rest when climbing stairs would not label themselves as disabled. Also, only physical functioning is included—9.8 million Americans aged 15 or over have mental or emotional disorders or impairments.

A more restrictive measure of disability involves *limitations in self-care and home management activities*, known respectively as "activities of daily living" (ADLs) and "instrumental activities of daily living" (IADLs). There are 8.2 million Americans aged 15 and above who have difficulty caring for themselves (getting into or out of bed, bathing, eating, dressing, toileting, or getting around within the home) and 12.3 million who have trouble managing the home (managing money, using the telephone, preparing meals, doing light housework, or getting around outside the home).

A person is considered to have a fairly severe disability if he or she needs the assistance of another person in performing these basic activities. An estimated 3.8 million people require personal assistance in self care, and 9.0 million need personal assistance in home management. A total of 9.5 million Americans aged 15 or over require personal assistance in one or more self-care or home-management activities, or 4.7% of the population.

All of the above numbers—population estimates and proportions—are derived from surveys that count only U.S. residents living in the community. Not included are people who reside in institutions, such as long-term care facilities, prisons, college dormitories, and mental hospitals. According to the 1990 Census, roughly 2.1 million Americans with disabilities live in institutions, most of them in nursing homes.

What Causes Disability?

Disability is most commonly caused by "hidden" conditions—ones not readily apparent to the casual observer. Although people often associate disability with its more visible manifestations—such as wheelchairs, the canes used by blind people, and sign language—the vast majority of people with disabilities do not require them.

In data from the 1992 National Health Interview Survey, back problems are the conditions most often named as the principal cause of disability, affecting 5.9 million Americans. Heart disease is second, limiting the activity of 4.0 million people. Next come arthritis (3.7 million), asthma (2.0 million), leg or foot problems (1.9 million), mental disorders (1.5 million), learning disability or mental retardation (1.4 million), diabetes (1.2 million), cancer (0.9 million), and cerebrovascular disease (0.8 million).

By contrast, the conditions most commonly thought of as disabling have much smaller prevalence. Paralysis is the main cause of activity limitation for 547,000 people, of whom 42,000 have quadriplegia and 47,000 have paraplegia. Visual impairment is the main cause of disability for 558,000 people, of whom 189,000 report blindness in both eyes; hearing impairment is listed as main cause for 654,000

Key Points

- People with disabilities number at least 41 million Americans, including 2 million living in institutions.
- The most common causes of disability are back problems, heart disease, arthritis, and asthma.
- Although the elderly have the highest disability rates, the majority (57.6%) of Americans with disabilities are of working age.
- Native Americans have the highest disability rate of all racial groups (17.6%). Asians and Pacific Islanders have the lowest rate (7.2%).
- Disability rates have been rising rapidly during the 1990's, due to increases in certain disabling conditions among youth.
- Disability rates are highest in rural areas.
- An alarming number of people with disabilities live in poverty, and government benefits are often insufficient to keep families with disabilities out of poverty.
- Disability rates are 3 times higher among people who did not attend high school than among those with college degrees.

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people, of whom 127,000 report deafness in both ears.

Age and Gender

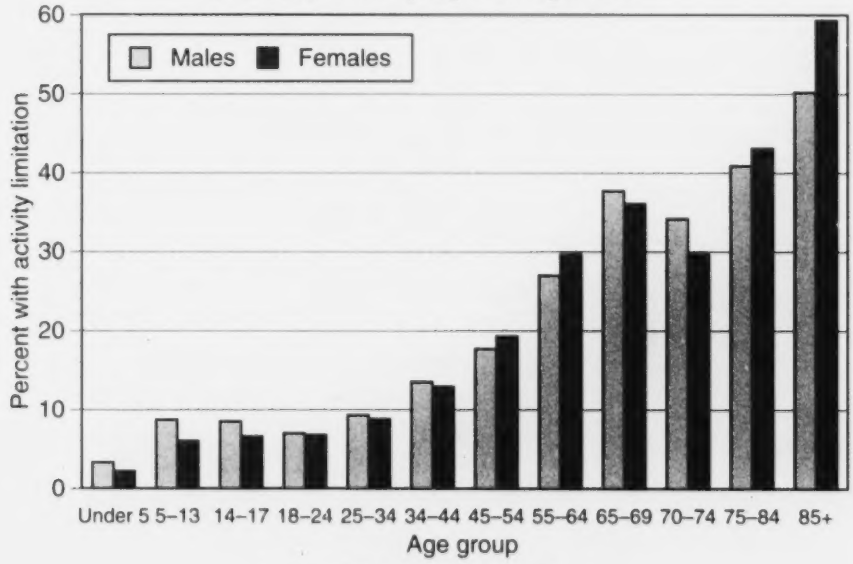
Disability affects people of all ages. Some 31.6% of people limited in activity are 65 or older, 10.7% are 18 or younger, and the remaining 57.6% are of working age. In general, the prevalence of disability increases with age, reaching its highest level among the very elderly, a majority of whom are affected.

The overall rate of activity limitation among the elderly is 38.8%, rising to 56.6% for those over age 85. For working-age adults, the rate is 14.1%, increasing from 6.9% for those aged 18–24 to 28.4% for those aged 55–64. And an estimated 6.1% of youth under 18 are limited in activity due to a chronic health problem or impairment.

Overall, a higher proportion of women experience activity limitation than men (15.4 versus 14.6%). This disparity is mostly due to the greater average longevity of women, coupled with the higher rates of disability among the elderly. Because 58% of the population over 65 is female, the similar disability rates for women and men in this age group (39.1 and 38.4%, respectively) result in much larger numbers of elderly women than men with activity limitations (7.0 versus 5.0 million).

Among the working ages, men and women also experience similar rates of disability (13.8% of men and 14.4% of women aged 18–64 are limited in activity). Among those under 18, however, rates vary substantially by gender: 7.1% of boys have disabilities, compared to 5.0% of girls. Most of this gap is accounted for by four major conditions—learning disabilities, mental retardation, hyperkinetic syndrome, and asthma—all of which are experienced much more often among boys than girls.

Disability rate by age and gender



Source: 1992 National Health Interview Survey

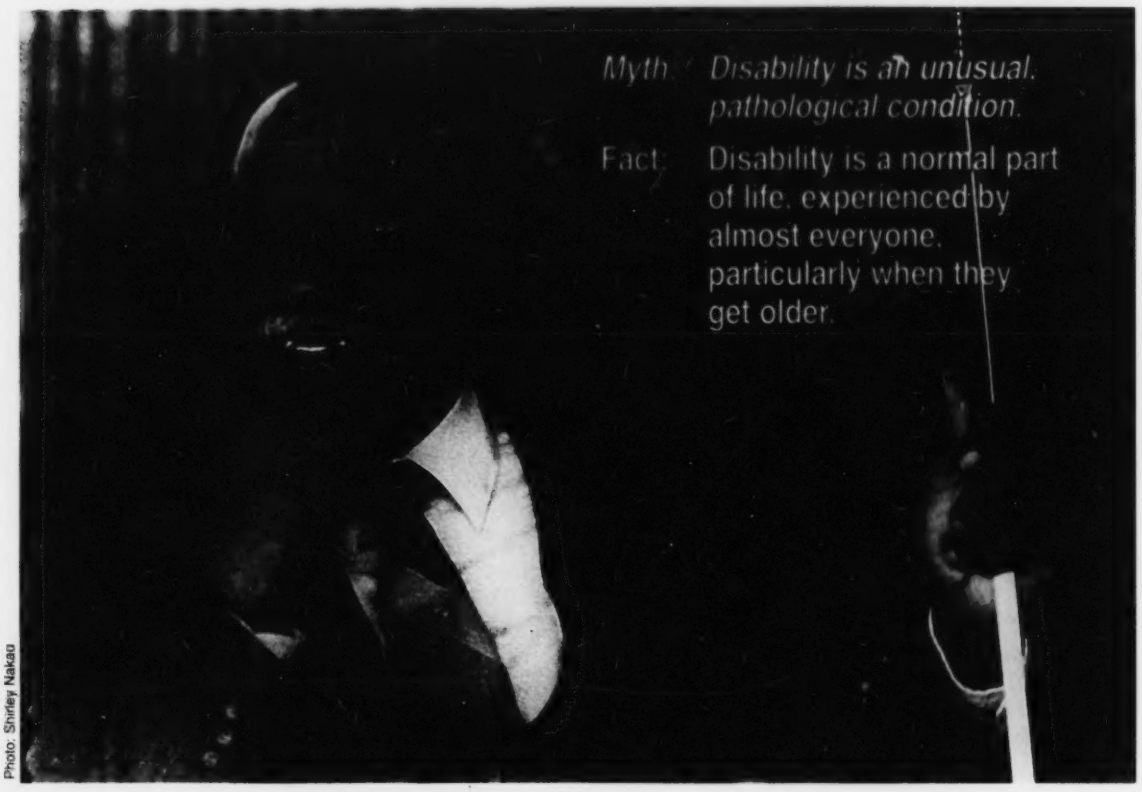

Myth: Disability is an unusual, pathological condition.
Fact: Disability is a normal part of life, experienced by almost everyone, particularly when they get older.

Photo: Shirley Nakata

Race and Ethnicity

Disability rates vary substantially among different racial groups. According to data from the 1992 National Health Interview Survey, Native Americans have a 17.6% rate of activity limitation, the highest of any racial group. African Americans and whites are next, at 15.9% and 15.3%, respectively, in both categories including people of Hispanic origin. By far the lowest rates are among Asians and Pacific Islanders, 7.2% of whom report activity limitation. Part of this disparity is explained by the younger average age of the Asian/Pacific Islander group.

Ethnicity also plays a role in disability rates. Those of Hispanic origin—the only ethnic group identifiable in the survey—report disability at a relatively low rate: 10.5%, versus 15.4% for everyone else.

Disability is a social phenomenon, resulting not only from medical considerations like disease and impairment, but also from the interactions of a person with society, which can either help or hinder access to support services, encourage or discourage independence, and provide or deny opportunities for jobs, recreation, socializing, and so on. Thus, differences in cultural background can have a substantial influence on reported rates of activity limitation. Economic factors are also important in determining access to education, jobs, health care, and personal assistance services, leading to further differences along racial and ethnic lines.

Increasing Disability Rates

Since the early 1970's, the prevalence of disability in the U.S. has risen substantially. A

relatively gradual trend is apparent in the 70's and 80's: In 1970, 11.7% of the population was limited in activity, according to the National Health Interview Survey, compared to 13.7% in 1990. Most of the increase was due to a demographic shift: The population grew older—the elderly comprised only 9.5% of the population in 1970, but had risen to 12.1% by 1990. Even though the disability rate among the elderly remained more or less constant, the overall rate of disability in the population went up.

Apart from this long-term trend, however, is a significant recent increase that is not explainable by demographic shifts. Between 1990 and 1994, the overall disability rate rose rapidly, from 13.7 to 15.0% in only 4 years. Some 33.8 million people reported activity limitation in 1990, compared to 39.1 million in 1994, an increase of 5.3 million people. But over the same 4-year period, the proportion of the population over 65 hardly changed. In fact, it dropped from 12.1 to 11.9%.

Younger people accounted for nearly all of the growth in disability rates. Children under 18 had a 1990 rate of activity limitation of 4.9%, which had risen to 6.7% by 1994. Among younger working-age adults, ages 18–44, the disability rate was 8.8% in 1990 and 10.3% in 1994. The increased rates translate to an additional 1.5 million children and 1.9 million young adults reported as having disabilities in 1994 compared to 1990. In contrast, the disability rates for older Americans rose only modestly during the period: from 21.8 to 22.6% for those aged 45–64 and from 37.5 to 38.2% for those aged 65 and above.

Rising rates of asthma, mental disorders, mental retardation, and learning disabilities account for much of the increase among youth. Young adults have experienced increased prevalence of orthopedic impairments, as well as mental and nervous disorders.

During the same period, other measures of disability have also shown steep increases. While 2.9% of working-age Americans said they were unable to work in 1990, the rate had increased to 3.7% by 1994. And the proportion of the non-elderly population needing

Disability rate, 1970–94

Source: National Health Interview Survey
Note: 1982 shift in the rate is due to a revision of the survey.

Photo: Shirley Nakao

personal assistance in self-care or home management, which had remained roughly constant at 1.6% during the mid- to late 1980's, rose to 2.1% in 1992 and has remained at approximately that level since. Both of these measures are indicative of fairly severe disabilities.

Between 1990 and 1994, the Social Security Administration also witnessed a steep increase in the number of people on its disability benefit rolls, both for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). During those 4 years, the number of beneficiaries increased by 0.6 million children and 1.7 million adults. People who receive these benefits have relatively severe disabilities; working-age adults must be judged to be unable to work at any job or business.

Where People with Disabilities Live

Three-quarters (74.8%) of people with disabilities live in metropolitan areas—31.6% in central cities and 43.2% in suburbs, according to the 1992 National Health Interview Survey. Most of the remainder (24.0%) live in non-farm rural areas. This last group has the highest rate of disability, however, at 17.6%, compared to 13.6% in farm areas, 13.7% in suburbs, and 15.4% in central cities.

Rates of overall activity limitation are highest in the South (16.3%) and lowest in the Northeast (13.7%). The Midwest and West fall in between, at 14.7% and 14.5%, respectively. Geographical differences in disability rates are probably due to a combination of socio-economic factors and actual differences in functional status.

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The 1990 Census reveals significant differences among the states in rates of work limitation (either inability to work or limitation in amount or kind of work, due to a chronic health problem or impairment). Some 12.6% of West Virginians had a work disability, twice the rate of the lowest-ranking state, New Jersey (6.2%). Other states with the highest work disability rates are in the South: Kentucky (11.4%), Arkansas (11.2%), Mississippi (11.0%), Louisiana (10.3%), and Oklahoma (10.2%). Maine (10.2%) and Oregon (10.0%) also have high rates, along with Tennessee (9.7%) and Montana (9.7%).

High Poverty Rates

On average, people with disabilities are significantly poorer than those without disabilities. Among working-age adults who are limited in their ability to work, the poverty rate is especially high: 30.0%, or three times the rate of those not limited in work (10.2%), according to the 1995 Current Population Survey. An even higher proportion of those who are unable to work live in poverty—38.3%.

Overall, 17.1% of people limited in any activity live in poverty, compared to 11.2% of people not limited in activity, according to the 1992 National Health Interview Survey. Among children, who have a high (18.4%) poverty rate overall, an astounding 28.4% of those with disabilities live in poverty, compared to 17.8% without. And among the elderly, the poverty rate is 11.4% for those with disabilities and 6.5% for those without disabilities.

Among working-age adults, the ability to work is critical in maintaining a decent family income. Those who are unable to work due to chronic disease or impairment have a median monthly family income that is less than half the national average ($1,396 versus $2,970 for men aged 18–64, $1,261 versus $2,755 for women), according to 1990 data from the Survey of Income and Program Participation. Among those unable to work, nearly half (46.5%) receive Social Security disability benefits, either SSDI (32.7%) or SSI (19.8%) or both (6.0%). Benefit levels under these programs are not high ($300 monthly for male and $288 for female SSI recipients in 1990; $634 for male and $425 for female SSDI recipients, on average). Often, these amounts are insufficient to raise families out of poverty. More than half (52.7%) of women receiving SSI live below the poverty line.

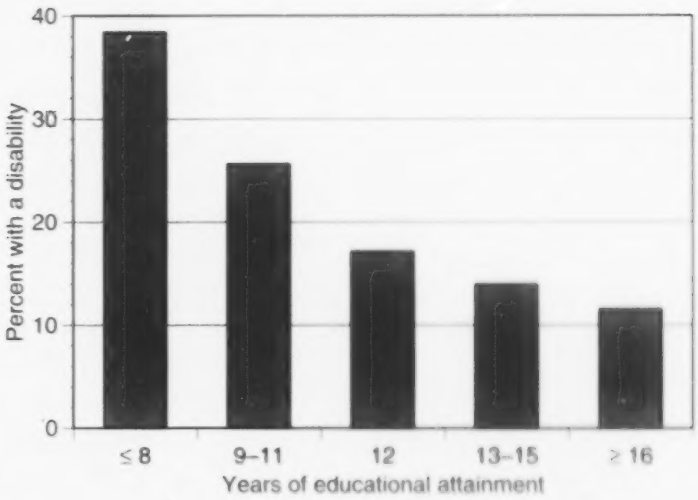
Educational Attainment

Disability rates are very strongly related to educational attainment. The more education a person has, the less likely he or she is to report limitation in activity. The disability rate for those without any high school education (38.4%) is more than 3 times that of those who have completed college (11.5%). People who have completed high school (12 years or more of schooling) have a 14.8% rate of activity limitation.

Four factors contribute to this striking correlation. First, people who grew up with disabilities in the past were often denied a full education. Second, better-educated people generally have greater flexibility in the kinds of work they can perform. They may therefore be less likely to view a purely physical limitation as impinging on their ability to do non-physical work; thus, higher educational attainment can effectively reduce disability rates.

Third, because average educational

Disability rate by level of educational attainment



Source: 1992 National Health Interview Survey

attainment has risen over the past several decades, older Americans often have less education than their younger counterparts. Since older people also have much higher disability rates, part of the correlation between education and disability is due simply to this historical trend. When disability rates are age-adjusted (in other words, when the rates are re-computed as if the age distribution of each group were the same as that of the general population), the 3-to-1 ratio of college graduates to those with no high school drops to around 2-to-1.

Finally, educational attainment is closely related to lifetime earnings. A poorly educated person may, as a result of reduced income, lack access to quality health care and may live and work under conditions that increase the risk of disability. Such a person may also lack the information needed to make wise choices regarding diet and lifestyle. Thus, educational level may indirectly influence the prevalence of chronic conditions and impairments that can cause disability.

Conclusions

The most striking feature of the population with disabilities is its size: People with disabilities now constitute the largest minority group in America. Although the exact number of people affected depends on which definition of disability is used, at least 39 million Americans living in the community have disabilities, in addition to the approximately 2 million living in institutions. The proportion of the population with disabilities has been rising gradually over the past few decades, due to the aging of the population. A recent, more rapid increase in the rate seems to be the result of actual increases in the prevalence of certain disabling chronic conditions and impairments among children and young adults.

Americans with disabilities are a highly diverse group. Although many people associate disability with paralysis, deafness, or visual impairment, far more people experience disability due to less visible conditions, such as heart disease, back problems, and arthritis.

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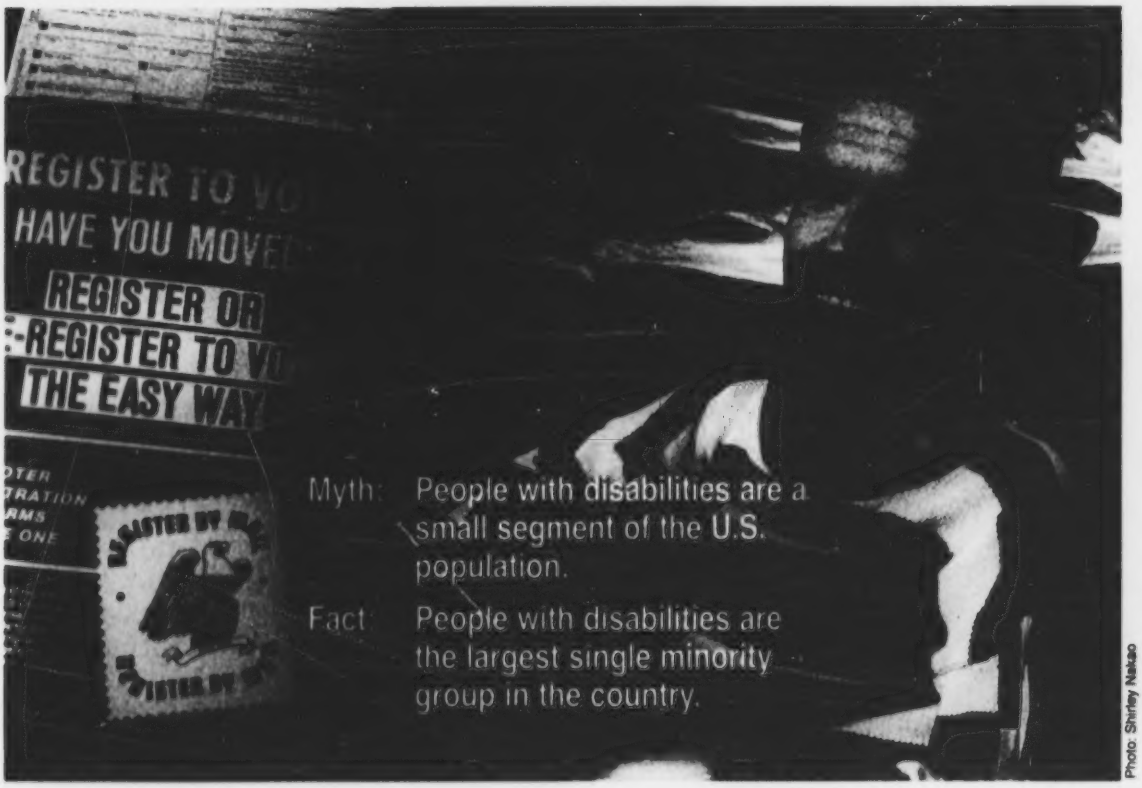
REGISTER TO VO
HAVE YOU MOVE
REGISTER OR
REGISTER TO VO
THE EASY WAY
Myth: People with disabilities are a small segment of the U.S. population.
Fact: People with disabilities are the largest single minority group in the country.

Photo: Shirley Nakao

While disability is sometimes associated with the elderly, a majority of people with disabilities are working-age adults. Significant numbers of children also experience disability—boys more often than girls. People of all races and ethnic groups experience disability, though rates differ among some of these groups. And although a large majority of people with disabilities live in metropolitan areas, the highest disability *rates* are found in rural settings.

Disability is associated with greater poverty and less education. In all age groups, people with disabilities are more likely to live in poverty than their non-disabled counterparts. The gap is largest among working-age adults with work disabilities: People denied access to jobs because of disability sink into poverty when government benefits are insufficient to keep them afloat. Increased employment opportunities are the key to greater economic equality for people with disabilities. Greater opportunities for education and training are also critical—a highly skilled person with a physical impairment is often able to shift to a less physically demanding job, thus remaining employed and escaping poverty.

Myths and Facts

Myth: *People with disabilities are a small segment of the U.S. population.*

Fact: **People with disabilities are the largest single minority group in the country.**

Myth: *Disability is an unusual, pathological condition.*

Fact: **Disability is a normal part of life, experienced by almost everyone, particularly when they get older.**

Myth: *Disability affects other people's families.*

Fact: **Nearly one-third (29.2%) of American families include at least one member with a disability. Disability affects nearly all families at one time or another.**

Myth: *Disability is mostly a problem for older people.*

Fact: **68.4% of people limited in activity are under age 65; 57.6% are of working age and 10.8% are under 18.**

Myth: *Disabilities begin at birth or in early childhood.*

Fact: **Most people with disabilities have no disability for much of their lives. Only one-fifth (21%) of people with disabilities acquired their disability before age 20, while roughly half (53%) have onset after 40.**

Myth: *Most people with disabilities use wheelchairs, or are blind or deaf.*

Fact: **Most disabilities are much less apparent. Heart disease and back problems are the two most common causes of activity limitation, affecting 7.9 and 7.7 million Americans, respectively.**

Myth: *Disability is primarily a health issue.*

Fact: **58.9% of non-elderly adults with disabilities rate their health as good to excellent. In many cases, disability is the result of a past health problem or an injury; such disabilities often do not necessitate continuing medical attention.**

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Data Sources

Rates of activity limitation, from the 1994 National Health Interview Survey, come from: National Center for Health Statistics. (1996). *Current Estimates from the National Health Interview Survey, 1994* (Vital and Health Statistics 193): NCHS, U.S. Department of Health and Human Services, Public Health Service.

Rates of work limitation, prevalences of conditions causing disability, disability rates by age and gender, disability rates by race and ethnicity, geographical variation in disability rates, poverty rates of people with activity limitation, and disability rates by educational attainment are derived from the analysis of the 1992 National Health Interview Survey contained in: LaPlante, M. P., & Carlson, D. (1996). *Disability in the United States: Prevalence and causes, 1992* (Disability Statistics Report 7): U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

Data on functional limitations and on limitations in self-care and home management activities are based on unpublished tabulations of the 1994–95 Survey of Income and Program Participation provided by John M. McNeil, U.S. Bureau of the Census.

The Census estimate of institutional residents comes from: U.S. Department of Commerce (1994). *Statistical Abstract of the United States 1994* (114th Edition): U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census.

The analysis on trends in disability rates is derived from: Kaye, H. S., LaPlante, M. P., Carlson, D., & Wenger, B. L. (1996). *Trends in Disability Rates in the United States, 1970–1994* (Disability Statistics Abstract 17): U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

Poverty rates for people with work disabilities come from unpublished tabulations provided by John M. McNeil, U.S. Bureau of the Census.

Income levels and benefit recipiency rates for those with work disability come from: LaPlante, M. P., Kennedy, J., & Trupin, L. (1996) *Income and Program Participation of People with Work Disabilities* (Disability Statistics Report 9): U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

The proportion of families with disabilities is derived from an analysis of the 1990 National Health Interview Survey contained in: LaPlante, M. P., Carlson, D., Kaye, H. S., & Bradsher, J. E. (1996). *Families with Disabilities in the United States* (Disability Statistics Report 8): U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

Data on disability onset come from the 1994 N.O.D./Harris poll: Leitman, R., Cooner, E., & Risher, P. (1994). *N.O.D/Harris Survey of Americans with Disabilities* (942003): Louis Harris and Associates, Inc., N.O.D.

Statistics on self-reported health status come from the 1989 National Health Interview Survey, analyzed in: LaPlante, M. P. (1993). *Disability, Health Insurance Coverage, and Utilization of Acute Health Services in the United States* (Disability Statistics Report 4): U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

Employment

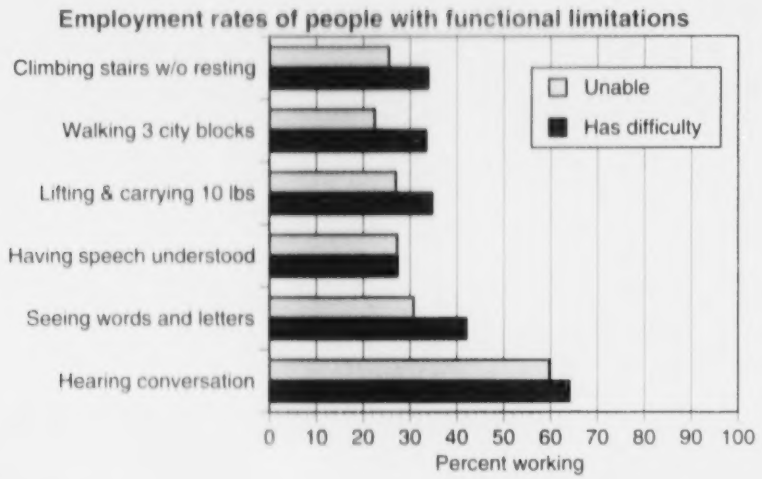
Employment rates for people with disabilities are shockingly low. According to data from the 1995 Current Population Survey (CPS), of the 16.9 million working-age Americans with health conditions or impairments that limit their ability to work, 12.1 million, or 72.2%, do not have jobs. For this group, employment would be the most direct route to greater social integration and fuller participation in mainstream life. Equally important is its potential as a path out of poverty for the 5.1 million—30% of the 16.9 million with work disabilities—who live below the poverty line.

A steady income is of critical importance, but it is only one of the many advantages of employment. A decent job can enhance self-worth, provide educational opportunities and skills training, give one's life structure and purpose, increase social contacts, and offer important fringe benefits such as health insurance, retirement pensions, travel opportunities, and paid vacation time. Lack of employment can lead to poverty, stagnation, loss of self-esteem, and isolation.

In the past, employment for people with certain disabilities often meant so-called *sheltered employment*—repetitive, often unskilled labor performed for low wages in a segregated environment, usually overseen by non-disabled supervisors. People with visual impairments might work at phone banks selling light bulbs, or those with mental retardation might be paid a few cents for each broom they assembled. These practices often exploited workers with disabilities, giving them few of the benefits of mainstream, *competitive employment*, such as financial independence and greater integration into society. Instead of marginalization and exploitation, people with disabilities want, need, and deserve equality and greater opportunity in the employment arena.

Employment Statistics

Lack of opportunity prevents many people with disabilities from working. The vast majority—67.9%—of those with work disabilities are not even in the labor force, meaning that they are neither working nor actively looking for work. Of those in the labor force,


Employment rates of people with functional limitations
Climbing stairs w/o resting
Walking 3 city blocks
Lifting & carrying 10 lbs
Having speech understood
Seeing words and letters
Hearing conversation
Unable
Has difficulty
0 10 20 30 40 50 60 70 80 90 100
Percent working

Source: 1994-95 Survey of Income and Program Participation

the unemployment rate of 13.4% is more than twice that for people without disabilities. A significant proportion of those with work disability say they are able to work, but are limited in the kind of jobs they can perform or in the length of their workday or workweek. The 1995 Current Population Survey classifies 6.5 million working-age Americans as limited but *not* prevented from working by their disability, of whom 2.5 million, or 38%, do not have jobs.

Employment rates vary greatly according to the nature and severity of the disability. According to 1994–95 data from the Survey of Income and Program Participation (SIPP), people with mobility impairments are the group least likely to be employed (roughly three-quarters do not have jobs), followed by blind people and those with mental retardation:

- only 22.0% of working-age wheelchair users and 27.5% of cane, crutch, or walker users are employed;
- only 25.5% of people unable to climb stairs, 22.5% of those unable to walk three city blocks, and 27.0% of those unable to lift and carry 10 pounds have jobs;
- 30.8% percent of blind people ("unable to see words or letters") work, while 43.7% of those with visual impairment are employed;
- only 35.1% of those with mental retardation have jobs;
- among those with mental or emotional disorders or impairments, 41.3% are employed;
- 64.4% of working-age adults with hearing impairments hold jobs, while 59.7% of those "unable to hear normal conversation" are employed.

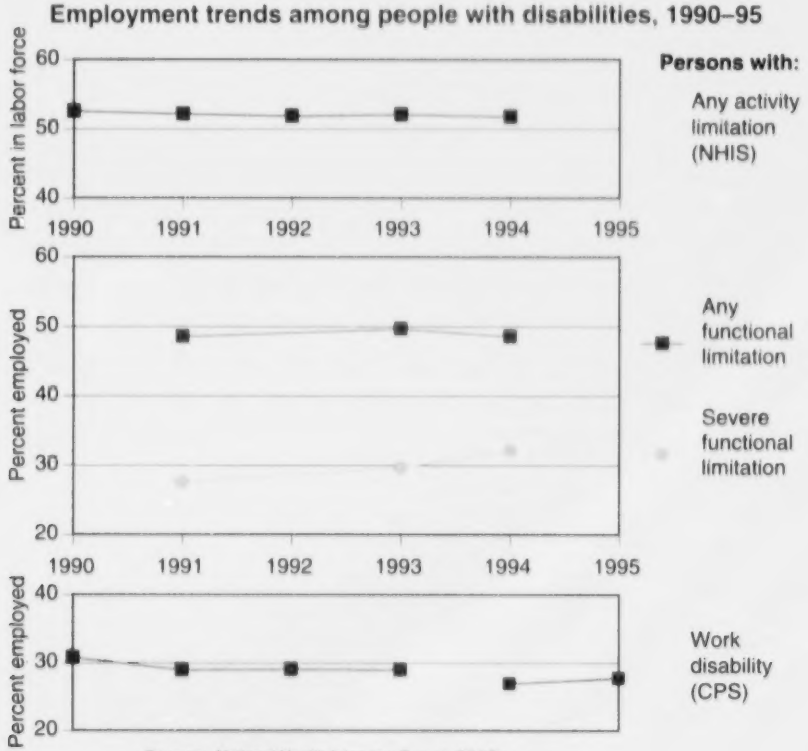
People with disabilities want to work. In a 1994 Harris poll, 79% of those without jobs said that they would prefer to be working. Within that group, 42% believed that they would be able to work if a suitable job could be found. Thus, people with disabilities have a strong work ethic, one that would propel a substantial number of them into the labor force if the right conditions were met—if they were offered decent jobs compatible

with their abilities and if barriers to employment were removed.

Although the Americans with Disabilities Act prohibits employers from discriminating on the basis of disability, data from four surveys fail to provide conclusive evidence of improvement in the employment status of people with disabilities:

- Data from the Survey of Income and Program Participation indicate that 32.2% of people considered to have *severe functional limitations* had jobs in late 1994, compared to 27.6% in late 1991. This increase is statistically significant. On the other hand, among people with *any* degree of functional limitation, the employment rate remained flat (48.6% in both 1991 and 1994).
- The employment rate for people with *work limitation* has also remained flat, as measured by the Current Population Survey: 27.8% of people with work disabilities had jobs in early 1995, compared to 29.0% in 1991 and 1993.
- The labor force participation rate has not changed significantly for people with *any activity limitation*, according to the National Health Interview Survey: The proportion of people either working or actively looking for work was 52.6% in 1990, 51.9% in 1992, and 51.8% in 1994.
- Harris poll respondents with *any disability* reported a 33% employment rate in 1986 compared to 31% in 1994—the difference is not statistically significant.

Employment trends among people with disabilities, 1990–95



Sources: National Health Interview Survey (NHIS), Survey of Income and Program Participation (SIPP), Current Population Survey (CPS)
Note: 1994–5 CPS data not directly comparable with prior years.

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Supported Employment

Supported employment is an innovative approach to providing integrated employment for people with certain disabilities, in particular mental retardation, developmental disabilities, and mental illness. These groups have traditionally been shunted into so-called sheltered workplaces, in which make-work or piecework activities are performed for little or no pay, and from which very few participants ever graduate to competitive work.

In contrast, *supported employment* is a form of assisted, competitive employment, in which on-the-job and other assistance is provided to workers who would otherwise not be able to take on mainstream jobs. Supported employment programs have enabled 105,000 people with severe disabilities to join the labor force, receiving real pay for real work.

Traditional vocational rehabilitation programs provide pre-employment training and job placement. In supported employment, however, "job coaches" go to the workplace to provide extra training and supervision to workers with disabilities, especially during the initial employment period, as well as to consult with employers and co-workers about problems that may develop. In addition, co-workers with and without disabilities can be enlisted to help reinforce skills, procedures, and schedules. People with disabilities either work singly with non-disabled co-workers or with others with similar disabilities in integrated settings.

Work is fully compensated at a regular wage, including the full benefits received by any other worker. One study indicated that 70% of supported employment workers at all levels of mental retardation retained their jobs for at least a year and that roughly 75% engaged in significant interactions with non-disabled co-workers.

It is too early to tell whether the ADA will ultimately succeed in increasing job opportunities. Its final employment provisions went into effect as recently as 1994, extending the anti-discrimination provisions to smaller companies of between 15 and 25 employees. Social change takes time, and job availability is influenced by economic factors unrelated to disability.

Furthermore, the statistics based on activity or work limitation should be interpreted with caution, since these measures may not be appropriate for detecting improvements in the employment situation of people with disabilities. A person who finds herself suitably employed, due to a job accommodation, may stop considering herself as limited in her ability to work, thus dropping out of the statistics entirely.

Barriers to Employment

People with disabilities face many barriers to employment. Principal among them is employer attitudes, cited by 40% of Harris poll respondents who were not fully employed. Employers often have the misguided notion that a person with a disability cannot handle a regular job or will often be absent from work, or that job accommodations will be too costly. People with mental impairments are particularly victimized by discrimination, despite studies indicating high rates of satisfaction among employers who have hired such workers, at little or no cost in terms of accommodation. Those with other "hidden" disabilities also encounter especially severe biases.

Physical barriers also limit access to jobs: Without accessible transportation, a person with a disability may not be able to get to and from work. Architectural barriers, such as stairs, curbs, or narrow entryways, can prevent a

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wheelchair user from leaving the house or entering a workplace. Obstacles in the work environment—desks at the wrong height, telephone receivers without amplification, inaccessible restrooms—can make it impossible to accept or remain at a job, in the absence of employer accommodations.

A comparatively low level of "human capital" can also limit job opportunities. In some cases, people with disabilities lack the education, skills, and experience that would make them fully competitive. People with disabilities often have less education and training than the average worker:

- while only 17.6% of non-disabled Americans lack a high school diploma, according to the 1992 National Health Interview Survey, the figure for people with disabilities is 33.3%;
- 34.5% of Americans without disabilities have college degrees, compared to only 9.6% of those with work disabilities;
- in the '94 Harris survey, 32% of people with disabilities cited lack of skills, education, or training as a reason they did not have full-time work.

Skills and training are often obtained on the job. Thus, people with limited employment histories often suffer by comparison to other workers who have held jobs throughout their adult lives.

Societal attitudes can be as much of an obstacle as any physical barrier. Public perception often equates disability with helplessness, and therefore inability to earn a living in a competitive environment. People with disabilities may not look for work because they do not believe they can overcome the barriers they face. They may not consider upgrading their skill levels, using technology to overcome obstacles to their functioning at a job, or demanding accommodations from employers. Or they may be cautious, reluctant to risk losing benefits by entering an uncertain labor market. Some 31% of Harris poll respondents mentioned benefits or health insurance as reasons for not seeking employment.

The Income Gap

Employment is crucial in keeping people with disabilities out of poverty. Among working-age people with disabilities who do not work, 39.7% live in poverty, according to the 1995 Current Population Survey (CPS), compared to 15.1% of those who work at least some of the time.

But even among those who do work, discrimination and other factors keep income levels of people with disabilities well below those of workers without disabilities. In 1995, men with disabilities earned on average only 72.1% of the amount non-disabled men earned annually, according to the Survey of Income and Program Participation (SIPP); women with disabilities made 72.6% as much as those without disabilities.

Although part of this gap is due to the greater rate of part-time employment among people with disabilities, income and poverty statistics show that even full-time work does not guarantee a living wage for people with disabilities. Considering people working full time during the entire year,

- the poverty rate of 4.6% among workers with disabilities is 60% greater than that of their non-disabled counterparts, according to data from the CPS;
- median monthly income for men with work disabilities averaged $1,880 in 1995, according to the SIPP—20% less

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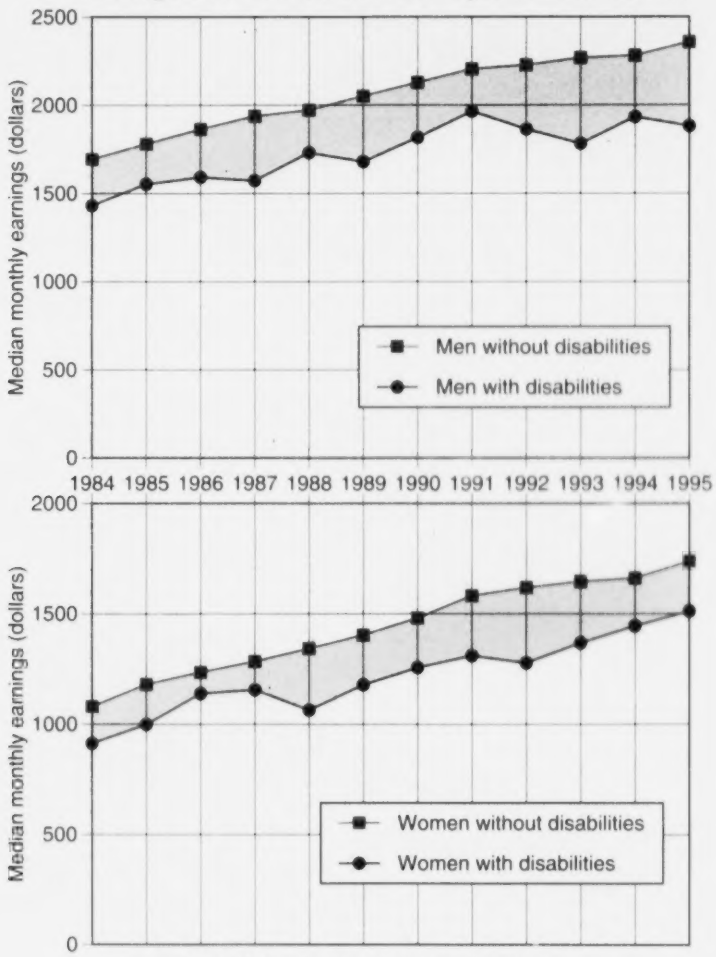
Earnings for Full-Time Workers Aged 16–64, 1984–95



Source: Survey of Income and Program Participation

than the $2,356 earned by their counterparts without disabilities;

- women with disabilities earned $1,511 monthly, or 13% less than the $1,737 figure for non-disabled women.

Job discrimination is at least partly to blame for the income disparity. In the 1994 Harris poll, 30% of working-age people with disabilities said they had encountered job discrimination directly related to their disability. Of those respondents who experienced discrimination, 63% had been refused a job, 29% had been denied a promotion, 33% had been given less responsibility than their co-workers, and 22% were paid less than co-workers doing similar work.

National statistics, both from the Harris poll and the SIPP, indicate that people with disabilities are underrepresented in executive and management positions and among business proprietors and overrepresented among unskilled workers and in the craft trades. Coupled with the reports of denied promotions, the dearth of people with disabilities in higher-paying positions may imply that a glass ceiling is preventing advancement to better jobs.

The income gap has only worsened during the past decade. According to data from the SIPP, men with work disabilities who had steady, full-time jobs earned 85% of the amount their non-disabled counterparts earned in 1984, compared to only 80% today. Poverty rates show a similar lack of improvement, according to the CPS: 14.8% of *working* people with work disabilities lived in poverty in 1989, compared to 15.1% in 1994; and 28.9% of *all* people with work disabilities lived in poverty in 1989, compared to 30.0% in 1994.

Workplace Accommodations: Inexpensive and Effective

A major goal of the ADA is to enable more people with disabilities to succeed in the labor force. Employers must provide "reasonable accommodations" to employees and job applicants who have disabilities, so long as these accommodations do not impose an "undue burden" on the employer. Despite the misconception that the cost of job accommodations is high, the facts indicate the opposite: The Job Accommodation Network (JAN), an information service sponsored by the President's Committee on Employment of People with Disabilities, reports that the cost of accommodations is typically very low, around $200 per employee with a disability. A recent Annenberg study of job accommodations made by Sears, Roebuck and Co. nationally found an even lower typical cost of less than $50.

Of the accommodations JAN recommends, many (17%) require no expenditure whatsoever. Such accommodations might include re-arranging an office to provide more maneuvering room, allowing a technician to sit for part of his work day, giving a job applicant with a learning disability extra time to take a test, or providing a reserved parking space to an employee with a mobility impairment. In the Sears study, a majority (69%) of accommodations incurred *no* direct cost, generally involving changes to work rules or schedules, job reassignments, or enhanced training or supervision.

In addition to the 17% that cost nothing, a further 52% of JAN's recommended job accommodations cost employers less than $500. Examples include purchasing wrist pads for a computer user with repetitive stress injury, a phone amplifier for a hearing impaired employee, an ergonomic chair for a back problem, or a special computer screen for someone with a visual impairment. An employer might hire a sign language interpreter for a training session, install soundproofing to enable a worker with a brain injury to concentrate, or install a railing in the restroom.

The level of employer satisfaction with such job accomodations is striking. JAN's numbers reveal that 82% of *employers* found the accommodations they made to be "extremely effective" or "very effective." More than half (53%) reported that they had been able to hire or retain a skilled employee, with the accommodation resulting in improved productivity. Many reported that the modifications they'd made had saved them the trouble and expense of hiring and training someone new. In general, employers reported substantial financial *benefit* as a consequence of small investments of time and/or money in accommodating workers with disabilities. At Sears, for example, administrative costs of replacing an employee average around $2000, a figure much greater than their typical accommodation costs.

Results from a 1995 Harris poll of employers confirm the low cost and high employer

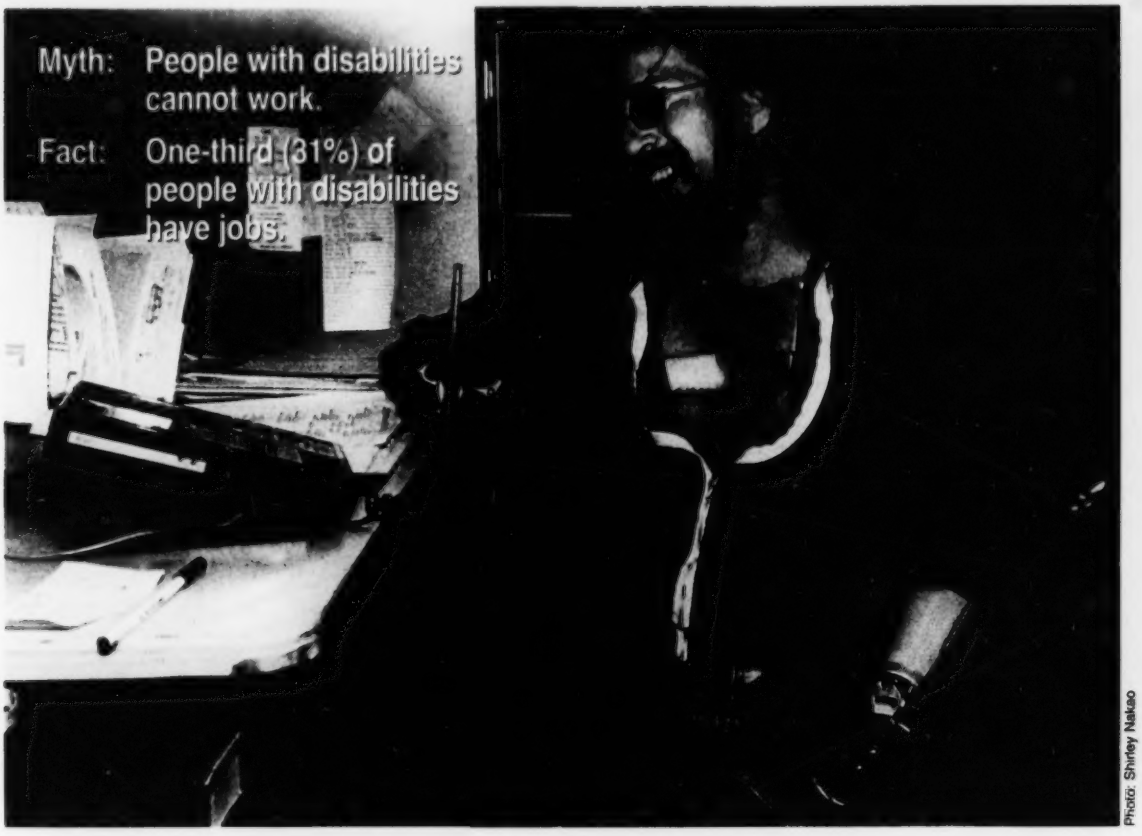


Photo: Shirley Nakao

satisfaction associated with reasonable accommodations:

- While 81% of employers have made accommodations for workers with disabilities (up from 51% in 1986), only 27% say that it costs more to employ a person with a disability than one without.
- Fully 82% say that the ADA "is worth the cost of implementation," and 80% report that the cost of accommodating people with disabilities has increased "a little or not at all" since passage of the ADA.
- A large majority (66%) also report that the amount of litigation has not increased as a result of the ADA.

Assistive Technology as a Gateway to Employment

Just as wheelchairs allow users to overcome mobility limitations, assistive technology can serve as a gateway to employment for people with certain types of disabilities. Electronic innovations, in particular, can help people with sensory and other impairments to perform tasks otherwise beyond their capabilities. In the '94 Harris Poll, 26% of respondents said that they would need special equipment or technology to perform the kinds of jobs they preferred.

Assistive technology has proved successful in accommodating jobs for people with disabilities. For example, a set of telecommunications devices for the deaf (TDDs) enables a deaf bank teller to communicate with customers by typing, a Braille printer allows a blind radio

announcer to read the news off the wire service, a tape recorder provides task reminders to an office worker with a mental disorder, and a computer program helps a programmer with a learning disability to communicate more clearly in writing. In an advanced use of assistive technology, people with cerebral palsy and other conditions that severely limit both speech and mobility can communicate effectively through a device called a "liberator," which combines an innovative keyboard, a computer, and a speech synthesizer. Although these devices may be more expensive than typical job accommodations, their cost is not prohibitive for most employers, and the benefits of employing the person with the disability generally outweigh the expense.

In the absence of government subsidies, people with disabilities may not be able to afford such equipment for home use, thus preventing them from gaining skills that might make them more competitive in the job market. Harris poll data indicate that, despite the ubiquitousness of computer technology in the general population, it is not always available to people with disabilities. Only about 1/4 of 1% mentioned using a personal computer as "special equipment or technology," and although 10% said they needed a computer, a screen enlarger, special keyboard or input device, speech synthesizer, or voice recognition software in order to perform their preferred job, only 1.3% actually owned such equipment.

Conclusions

Despite the equal opportunity provisions of the ADA, the evidence for increased employment rates for people with disabilities is not yet convincing. Because having a job can not only provide an escape from poverty

Key Points

- A large majority—72.2%—of working-age Americans with work disabilities do not have jobs. Nearly a third (30%) live in poverty.
- The unemployment rate for people with disabilities, 13.4%, is more than twice that of those without disabilities.
- People with mobility impairments, blindness, and mental retardation are the least likely to have jobs. Those with hearing impairments are the most likely to be working.
- A large majority (79%) of people with disabilities who are not employed would rather be working. Of these, 42% say they would be able to work if a suitable job could be found.
- The low employment rate for people with disabilities has not gone up substantially since the passage of the ADA.
- Employer attitudes are a principal barrier faced by people with disabilities who are looking for work: 30% of working-age people with disabilities have encountered job discrimination.
- Low levels of "human capital"—education, skills, and experience—often make finding a job difficult for people with disabilities.
- Working people with disabilities earn substantially less than their non-disabled counterparts—roughly 72 cents to the dollar.
- Workplace accommodations for people with disabilities are effective and inexpensive, averaging around $200 per employee.
- Although assistive technology could improve the employability of many people with disabilities, greater access to such equipment is needed.
- Vocational rehabilitation can be effective, but it is not widely available.

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and dependency, but also lead to a fuller life and a greater integration into society, increasing job opportunities should remain a major focus of disability policy. Employing people with disabilities is beneficial not only to those who get jobs, but to employers and to society at large.

Discrimination must be addressed through employer education and more rigorous enforcement of the law. Employers need to be better educated about the capabilities of workers who have disabilities, about the efficacy and low cost of job accommodations, and about the high level of satisfaction among those employers who have made efforts to hire and retain workers with disabilities. More training and support is also needed to help employers who are unfamiliar with the needs of workers with disabilities or who lack the resources to make their work environment more hospitable. In addition, better enforcement of anti-discrimination provisions of the ADA is needed, in order to convey a clear message that people with disabilities have a right to fair treatment in the workplace.

Public policy also must change to promote employment instead of dependency. The U.S. government currently spends forty times as much on cash benefits for people with disabilities as it does on enabling them to work. Government funded vocational rehabilitation programs have a success rate of 43 to 63%, depending on the disability, in placing clients in competitive, full-time employment, but only 10% of new SSI and SSDI beneficiaries are offered such services. People with disabilities must be afforded greater access to vocational rehabilitation, job placement, and supported employment programs.

Our society must invest in improving the "human capital"—education, skills, job experience—of people with disabilities in order to make them fully competitive. Education and skills can greatly enhance a person's job prospects, but people with disabilities frequently lack the training and experience necessary to acquire a decent job. Past discrimination is often at the root of such deficiencies, which must be compensated for by educational and training programs to improve job opportunities.

Myths and Facts

Myth: *People with disabilities do not have jobs because their disability prevents them from working.*

Fact: **Many people with disabilities (31%) do work, and many more (at least an additional 23%) could work if offered suitable jobs.**

Myth: *People who are blind or deaf, or who have cerebral palsy, quadriplegia, or other severe disabilities, cannot be employed in ordinary jobs.*

Fact: **A blind programmer can use a computer equipped with a speech synthesizer. A deaf bank teller can communicate with customers using a telecommunications device. A person with cerebral palsy can get around on the job using a motorized wheelchair, and communicate with co-workers using a special keyboard and synthesizer device. Many functional limitations can be overcome through creative use of technology.**

Myth: *People with mental retardation and other mental impairments can't hold steady jobs.*

Fact: **Many people with mental impairments do work. Supported employment helps people with mental retardation hold regular, full-time, paid jobs.**

Myth: *People with disabilities can get government handouts, and so they don't want to work.*

Fact: **Some 79% of people with disabilities who do not work say that they would rather be working.**

Myth: *The ADA has meant equal employment for people with disabilities.*

Fact: **The national employment rate for people with disabilities remains low, even after the implementation of the ADA.**

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Data Sources

Employment and poverty rates from the 1994 and 1995 Current Population Surveys are derived from unpublished tabulations provided by John M. McNeil, U.S. Bureau of the Census. Employment rates from the 1990–93 Current Population Surveys come from the *Poverty in the United States* series of reports published by the U.S. Bureau of the Census.

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Labor force rates from the National Health Interview Survey are derived from an analysis in: Trupin, L., Sebesta, D. S., Yelin, E., & LaPlante, M.P. (1997) *Trends in Labor Force Participation Among Persons with Disabilities, 1983–1994* (Disability Statistics Report 10): U.S. Department of Education, National Institute on Disability and Rehabilitation Research.

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The Annenberg study of job accommodations at Sears is described in: Blanck, P. D. (1996). *Communicating the Americans with Disabilities Act: Transcending Compliance: 1996 Follow-up Report on Sears, Roebuck and Co.*: Annenberg Washington Program, Communications Policy Studies, Northwestern University.

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Social Integration

People with disabilities are 5 times more likely than non-disabled people to say that they are dissatisfied with their lives (24% vs. 5%, among adult respondents to the 1994 Harris survey). Social isolation is a major reason cited for this unhappiness. Half (51%) of people with disabilities say that lack of a full social life is a problem for them. Only financial concerns are mentioned more often, by two-thirds of respondents.

Independent Living vs. the Medical Model

Independent living has become a major focus among Americans with disabilities. A main goal of the independent living movement is greater social integration, a shift from being invisible to being active participants in society.

People with disabilities have traditionally been kept segregated from mainstream society, either hidden away in institutions or shut in at home. In the past, disability was treated purely as a medical issue—a pathological condition to be attended to by doctors, nurses, and rehabilitation specialists. When no cure was forthcoming, the disability was looked upon as a personal tragedy, a defect that society did not want to be reminded of. But the disability movement has replaced the medical model of disability with one that focuses on the needs and desires of people with disabilities. Rather than seeing themselves as patients, those with disabilities have begun asserting their right to live independently, like anyone else, and to obtain services and support over which they themselves retain control. Services might include personal assistance (such as help dressing, getting around, or preparing meals), and support could involve financial assistance or staff to help with household management.

Social integration is also a key element of national disability policy, as delineated in the Americans with Disabilities Act. Participating in society can include living in the community, working in mainstream jobs, receiving education in regular classrooms with non-disabled students, attending cultural and social events, maintaining a network of friends, and engaging in other leisure activities.

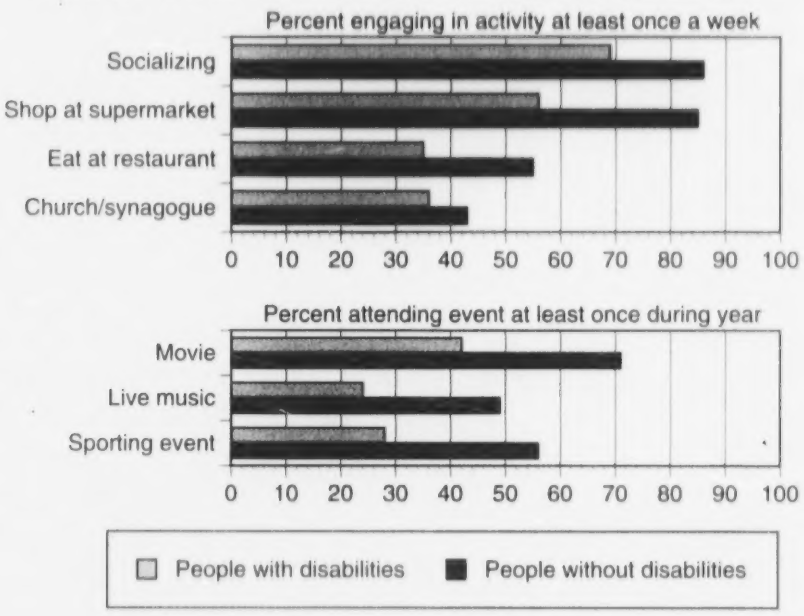
People with Disabilities are Socially Isolated

Some 64% of adults with disabilities say that they are not able, as much as they would like, to get around town, attend cultural or sporting events, or socialize with friends. More specifically, 30% of people with disabilities socialize with close friends, relatives, or neighbors less often than once a week, compared to only 14% of people without disabilities. Twice as many people with disabilities as those without (58% vs. 29%) said they had not gone to see a movie in the previous year. Three-fourths hadn't attended a live music performance (76%, compared to 51% for those without disabilities), and two-thirds hadn't been to a sporting event (71%, vs. 43% of those without disabilities). Two-thirds (65%) of people with disabilities go out to eat less often than once a week, compared to less than half (45%) of non-disabled people. Church attendance is lower for people with disabilities (49% attend at least once a month, compared to 59% for those with no disabilities). And, while almost all American adults without disabilities go food shopping at least once a week (85%), only just over half (56%) of those with disabilities do so.

Although greater social integration for people with disabilities has long been sought, comparison of the Harris 1986 and '94 surveys shows little evidence of progress. The proportion of people socializing regularly with others has not changed significantly, nor have the figures on attending cultural events, dining out regularly, attending church, or going food shopping. Overall, the same proportion (24%) reported general dissatisfaction with their lives in 1986 and in 1994.

On the other hand, the vast majority (75%) of people with disabilities questioned in 1994 said that access to restaurants, theaters, stores, and museums had improved during the four

Participation in social, cultural, and commercial activities


Percent engaging in activity at least once a week
Socializing
Shop at supermarket
Eat at restaurant
Church/synagogue
0 10 20 30 40 50 60 70 80 90 100
Percent attending event at least once during year
Movie
Live music
Sporting event
0 10 20 30 40 50 60 70 80 90 100
People with disabilities
People without disabilities

Source: 1994 N.O.D./Harris Survey

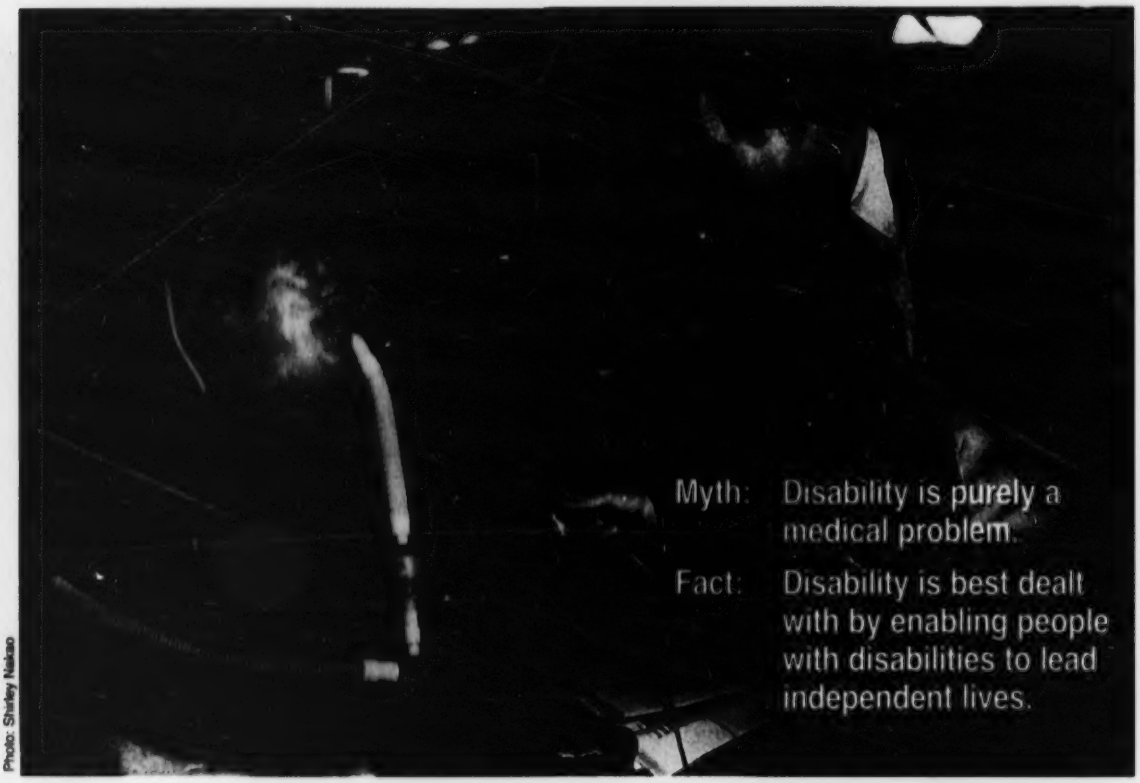

Myth: Disability is purely a medical problem.
Fact: Disability is best dealt with by enabling people with disabilities to lead independent lives.

Photo: Shirley Nakao

years since enactment of the ADA. Although greater accessibility does not seem to have translated directly to measurable increases in the use of such facilities, it may be too soon to judge. Nearly two-thirds of respondents (63%) said that the quality of life for people with disabilities had improved during that four-year period.

Nursing Homes and Other Institutions

According to Census data, 2.1 million Americans with disabilities lived in institutions in 1990. The majority—1.8 million—lived in nursing homes, while 129,000 lived in mental hospitals or residential treatment centers and 214,000 lived in homes, schools, or hospitals for people with physical or mental disabilities. By comparison, some 33.8 million Americans not living in institutions reported activity limitation in 1990; thus, the vast majority of people with disabilities live in the community, rather than in formal institutions.

Census figures show that the number of nursing home residents—mostly elderly, the majority with mental disorders—has undergone an enormous increase, rising from 470,000 in 1960 to 928,000 in 1970, 1.4 million in 1980, and 1.8 million in 1990. By contrast, the number of people living in other types of institutions, mainly for the non-elderly with disabilities, has fallen sharply during the same period. Only one-fifth as many people lived in mental hospitals and residential treatment centers in 1990 as in 1960 (129,000 vs. 630,000), and the population living in other institutions has decreased by one-third (309,000 in 1960 compared to 214,000 in 1990).

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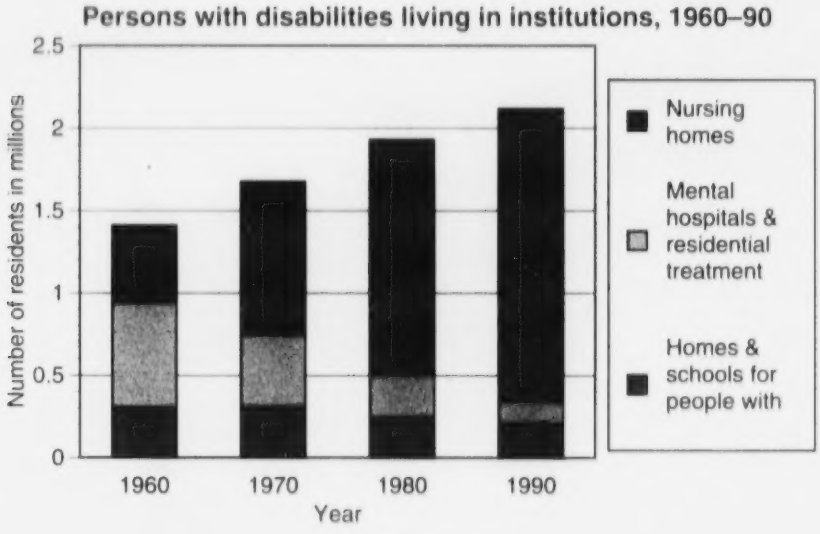

Source: Decennial Census

Overall, the number of Americans with disabilities living in institutions has been increasing instead of decreasing, from 1.4 million in 1960 to 2.1 million in 1990. The substantial gains that have been achieved in avoiding institutionalization for non-elderly people with disabilities have been more than offset by the increase in the elderly population living in nursing homes. It is now older people with disabilities who find themselves shunted off to institutions to live out the remainder of their lives.

Community-Based Services vs. Institutions

One of the major factors keeping people with disabilities in nursing homes is a lack of community-based, independent living services, such as adequate in-home attendant care services. Because national policy has favored institutional, residential-care programs over in-home support services, people with disabilities who could otherwise live in residential settings are forced to enter or remain in nursing homes, at *greater* cost to taxpayers. The role of the nursing home industry, which lobbies to maintain the focus on institutional care, is a major factor in this misallocation of social resources. Another factor is the mistaken assumption that people with disabilities are "sick," and thus need to be cared for in medical institutions.

In 1995, disability activists won a major victory against forced institutional care. The state of Pennsylvania was allocating its resources so that people with disabilities who needed attendant care were being forced to stay in nursing homes simply to get such supportive services. The state, while admitting that community-based attendant care services would cost less, nevertheless argued that it had no obligation to allocate its resources to enable people with disabilities to live in the community rather than in institutions. The court ruled otherwise, holding that the ADA requires public entities to structure supportive services in order to enable recipients to obtain the most integrated setting. Requiring admission to a nursing home to receive help with bathing and other personal care services, the court said, constitutes unnecessary segregation.

The disability community itself has organized to advocate for an end to unnecessary nursing home care. ADAPT, a disability rights organization committed to non-violent civil disobedience tactics, has recently made such forced institutionalization a focus of protest actions. Much change needs to occur, however, before people with disabilities are able to live free of fear that they will be forced into institutions just to obtain help with basic life activities.

Substandard Nursing Home Facilities

The shockingly poor state of nursing homes in the United States makes the increased reliance on them especially disturbing. Instances of patient abuse and neglect continue to be commonplace in these facilities, despite improvements brought about as a result of nursing home reform legislation contained in the 1987 Omnibus Budget Reconciliation Act (OBRA '87). Recent episodes cited by California Advocates for Nursing Home Reform include medication injected into the wrong patient, poor food storage leading to serious illness, patients left lying in their own excrement, forcible restraint resulting in serious injury, and patients physically and verbally attacked by staff.

According to 1995 figures from the Health Care Financing Administration, 18% of nursing homes nationally were found to be deficient in "providing care that enhanced human dignity"; 25% did not store, prepare, and serve food in sanitary conditions; 28% failed to adequately prepare the comprehensive assessment of residents required under OBRA '87; and 11% were found to be giving patients unnecessary drugs. Some 17% of nursing homes were found deficient due to overuse or misuse

Key Points

- Although social integration is a main goal of disability policy, isolation is a problem for half (51%) of all people with disabilities.
- People with disabilities socialize with friends, eat out, go to see movies, shop, and attend church much less often than do non-disabled people.
- Large numbers of Americans with disabilities continue to live in institutions, most of them (1.8 million) in nursing homes.
- Despite recent improvements, too many U.S. nursing home residents continue to suffer abuse and neglect, or are subject to unneeded physical and chemical restraints.
- People with mental retardation and developmental disabilities increasingly reside in small group homes, but significant numbers—including many with only mild or moderate retardation—continue to live in dehumanizing, state-run institutions.
- Although families often provide critical support and assistance to members with disabilities, people with disabilities are twice as likely as non-disabled people to be living alone.
- Children with disabilities are increasingly being educated in mainstream settings, which improves their academic and social skills, self-esteem, job prospects, and degree of interaction with non-disabled peers.
- The benefits of mainstreaming also extend to children without disabilities, who learn greater tolerance and acceptance as a direct result of interacting with children who have disabilities.

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of physical restraints; 20% of nursing home residents nationally are estimated to be under some sort of physical restraint. Chemical restraints are even more widely used; 1% of facilities were cited for overuse of drugs to keep patients docile.

Statistics on the desires of institutional residents are hard to come by, but anecdotal evidence certainly suggests that many such persons would move into the community if they were given the option. But financial barriers often preclude such a transition. Medicare, Medicaid, and other government programs generally pay for institutional care, but not personal assistance services outside the institution, even when these services would be substantially less costly to the taxpayer. Thus, government regulations discourage greater social integration of some people with disabilities and directly contradict stated national policy.

MR/DD Residences: Too Many Institutions

Despite the clear advantages of community living, an estimated 75,000 people with mental retardation and developmental disabilities (MR/DD) continue to live behind the walls of large government-run institutions, according to 1992 data from the National Residential Information Systems Project. This figure includes many identified as having only "borderline" to "moderate" retardation, people who could certainly benefit from greater levels of social integration—in 1987, 18% of the residents of very large state institutions and 46% of those in other large institutions had been so classified. Denial of basic freedoms and opportunities to these individuals is especially troubling.

But significant progress has been made. In the past, people with MR/DD were assumed incapable of making life decisions, and were routinely sent to live out their lives in inhumane, state-run institutions. These facilities were warehouses, even prisons, in which residents were given little freedom, only the most repetitive and menial jobs, few opportunities to form ties with non-disabled people, and hardly any hope of ever leaving the institution.

Nearly 30 years ago, the situation began to change dramatically. States began to reduce the populations within these large-scale institutions, eventually shutting many of them down. The number of people with MR/DD in large, state-run institutions dropped 62%, from 195,000 in 1967 to 75,000 in 1992. Many of those moved out of the large institutions were transferred to smaller settings. While only 16% of residential service recipients with MR/DD lived in community residences with 15 or fewer inhabitants in 1977, 59% lived in such residences in 1992, mostly (41%) in group homes of 6 or fewer residents.

Smaller, community-based settings are more likely to provide opportunities for employment, association with outside family and friends, and a greater level of self-determination. Numerous studies have documented significant improvements in social, communication, self-care, academic, and vocational skills for people who are transferred from large state institutions into smaller, community living arrangements with appropriate supports.

Living Alone Leads to Social Isolation

People with disabilities are more than twice as likely to live alone as those without disabilities (19.6% vs. 8.4%), according to data from the 1990 National Health Interview Survey. A significant part of this difference is due to the older average age of people with disabilities,

coupled with the fact that older people are more likely to be widowed. Whereas 28.6% of community-resident older Americans live alone, one-third (33.9%) of those over 65 with disabilities live by themselves. The general problem of social isolation among the elderly is therefore accentuated for those who have disabilities.

Younger adults with disabilities also live alone in greater proportions than do their non-disabled counterparts. Among people aged 18 to 44, 11.4% of those with disabilities live alone, compared to 9.1% of those without. Statistics also indicate that people who acquire their disabilities early in life are more likely to delay marriage or remain single—40.7% of 25 to 44-year-olds with disabilities lack a live-in spouse or partner, compared to only 29.7% of the non-disabled population in that age group. The pattern suggests that, for people who experience disability at birth or in their youth, opportunities for forming families later in life may be limited. Greater social isolation may be the result.

Small, qualitative studies suggest that disability limits the ability of women, in particular, to find romantic partners and thus to form families. In addition, women who experience severe disability may be more likely to see their relationships dissolve as a result of the disability: In one study, half of the women who had relationships prior to their spinal cord injury endured the break-up of those relationships following their injury.

Because family members often act as the primary source of support and assistance for people with disabilities, lack of family can lead to reduced opportunities for participation in society. When a disability is severe, family support can mean the difference between independence and dependence, between continued living in the community and institutionalization. Thus, family life can be crucial in fostering social integration.

Education as a Path to Social Integration

As with other minority groups, greater social integration for people with disabilities is probably best begun in childhood. Compared to children who are segregated into special schools or classes, students with disabilities who receive their education in regular classrooms, along with their non-disabled peers, generally have a head start at participating more fully in society. And children without disabilities who grow up exposed to disability in school are less likely to develop misconceptions and prejudices about disabilities.

Mainstream education is therefore beneficial both to most students with disabilities and to society. Contrary to the old practice of placing children with disabilities in live-in facilities or in separate classes in public schools, federal law now supports mainstreaming as national policy. The Individuals with Disabilities Education Act (IDEA) requires that "to the maximum extent appropriate, children with disabilities . . . should be educated with children who are not disabled"; separate schools and classes are to be used only as a last resort.

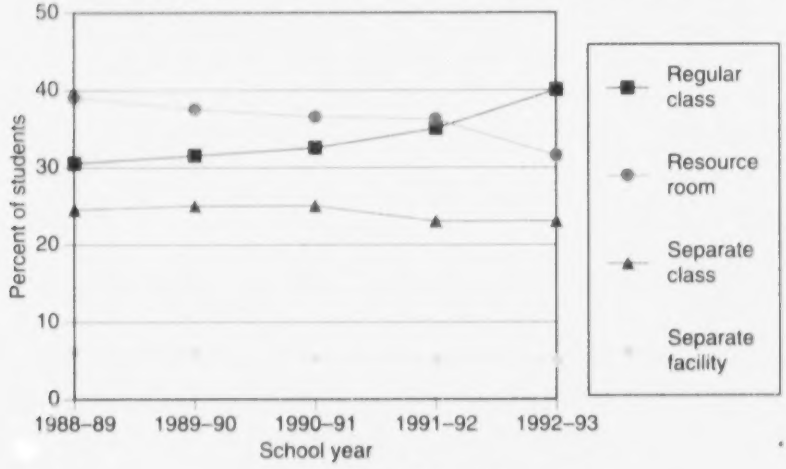
Department of Education statistics indicate that 5.4 million children with disabilities attended school in the United States in the 1993–94 school year, representing 11.6% of total school enrollment. Of these, 4.8 million were over 5 years of age, including 2.4 million with learning disabilities, 1.0 million with speech or language impairments, 0.6 million with mental retardation, and 0.4 million with serious emotional disturbances.

Each year, an increasing proportion of students with disabilities attend regular classes along with their non-disabled peers. During the 1992–93 school year, 40% of students with disabilities received mainstream schooling, spending the bulk (at least 79%) of their school day in regular classes. During 1988–89, the figure was only 30%. In 1992–93, 32% of students with disabilities attended regular classes for part (40–79%) of the school day, spending the rest of the time in "resource rooms"; the proportion was a much higher 39% for 1988–89. Most of the remaining students were educated in separate classes (24% in both years) or separate schools (6% in 1988–89 vs. 4% in 1992–93), while a small fraction (less than 1% each in 1992–93) lived in residential facilities or received schooling at home or in the hospital.

Younger children with disabilities are more likely to receive mainstream education. During the 1992–93 school year, 50% of elementary school students (ages 6–11) with disabilities attended regular classes. An additional 26% spent a portion of their school day in resource rooms, with the remainder of the time spent in regular classes. The degree of mainstreaming also varies considerably by disability: Among 6- through 21-year-olds with disabilities, those with speech or language impairments were most likely to attend regular classes (82%), followed by those with visual impairments (46%), orthopedic impairments (35%), learning disabilities (35%), and hearing impairments (30%). Students least likely to attend regular classes were those with mental retardation (7%), multiple disabilities (8%), autism (9%), and deaf-blindness (12%).

A 1989 Harris survey of educators and parents of children with disabilities pointed to clear benefits of mainstream education: 88% of educators and 81% of parents said that mainstreaming was "good" or "somewhat good" for the child's educational performance, 93% of educators and 86% of parents said that it benefited students' social skills, and 95% of educators and 81% of parents said that it had improved self-esteem. The children themselves report that they are much more likely to

Educational setting for students with disabilities, 1988–93



Source: U.S. Dept. of Education

Learning Disabilities

Some 2.4 million children, just over half of those enrolled in special education programs, are identified as having learning disabilities. Neurological in origin, learning disabilities impede a person's ability to store, process, or use information. Learning disabilities can affect the ability to read, write, listen, and speak, as well as to solve math or word problems, creating a gap between ability and performance.

Learning disabilities, which affect adults as well as children, vary widely in type and severity.

- **Dyslexia** is a difficulty with language processing and its impact on reading, writing, and spelling.
- **Dysgraphia** refers to difficulty with writing; problems might be seen in the motor patterns used during writing, as well as difficulties with spelling and written composition.
- **Auditory discrimination,** a key component of efficient language use, presents problems for some people with learning disabilities, who may have difficulty perceiving differences between speech sounds and sequencing these sounds into meaningful words.
- **Visual perception** is also critical to the reading process; it addresses the ability to notice details and assign meaning to what one sees.

Without early identification and intervention, learning disabilities can contribute to loss of self-esteem, truancy, dropping out of school, delinquency, poor literacy skills, and other problems.

Because learning disabilities are not a visible cause of disability, many people mistakenly believe that they are often used as an excuse for poor performance. But a recent court decision upheld the legitimacy of learning disabilities as valid reasons for students to request accommodation under the law.

In a landmark decision, a federal court found that Boston University violated the ADA and the Rehabilitation Act by requiring overly stringent documentation for students with learning disabilities. The court sharply criticized BU and its president for reliance on "misinformed stereotypes" and the "unfounded belief" that students with learning disabilities were unmotivated. The decision is noteworthy for its findings that (1) learning disabilities are real and scientifically based, (2) BU never discovered a single instance of "faking" a learning disability, and (3) students with learning disabilities can be highly intelligent and are often greatly motivated.

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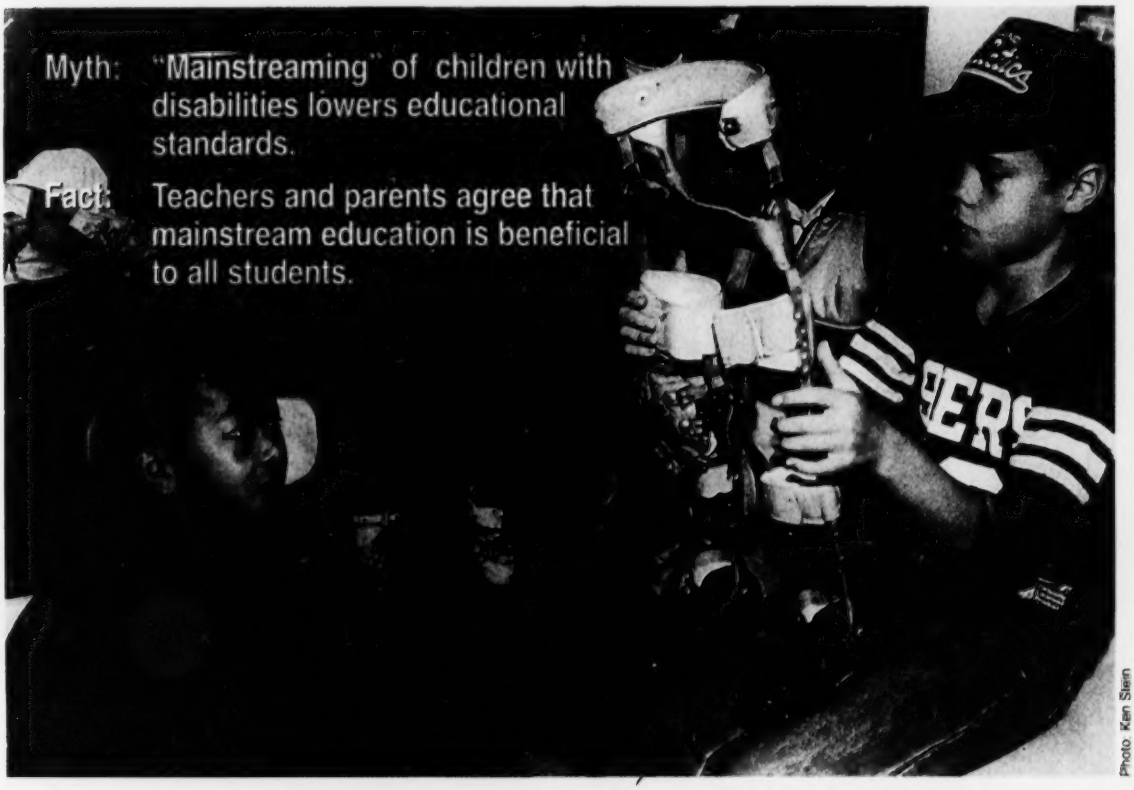
Myth: "Mainstreaming" of children with disabilities lowers educational standards.
Fact: Teachers and parents agree that mainstream education is beneficial to all students.

Photo: Ken Stein

have made friends with non-disabled students when educated in regular classrooms (80% had mostly non-disabled friends) than in special classes (34%).

There is also evidence of a trend toward greater high-school completion rates for students with disabilities (up from 55% in 1985 to 64% in 1992, according to Department of Education figures), who have increasingly been educated in mainstream settings. Because a high school diploma leads to greatly increased job opportunities, this trend translates directly to greater future labor force participation.

Mainstreaming also provides substantial benefits to non-disabled students. When the 1989 Harris poll surveyed teachers about the effect of students with disabilities in the classroom on those *without* disabilities, 29% volunteered that they had observed greater acceptance or tolerance, 20% mentioned greater understanding of the difficulties facing those with disabilities, 14% said greater compassion and sensitivity, 13% said willingness to help and work together, and 8% mentioned greater awareness of the differences in people. Only 6% brought up any negative effect on the classroom environment. Studies have shown no increase in disruptions or decline in standardized test performance among non-disabled students when children with disabilities are placed in the classroom.

A mainstream education is not necessarily appropriate for all students with disabilities, however. Deaf students, for example, can benefit significantly from opportunities to become proficient in American Sign Language, which may be best practiced in separate classrooms.

Conclusions

Although full participation in society is one of the major goals of the ADA, too many people with disabilities remain isolated. Many lack a full social life, means and opportunities to venture out into the world, and the support and services they would need to lead complete, independent lives. Although there are indications of improvements in the accessibility of cultural venues, restaurants, stores, and public buildings, these gains have not yet translated directly into increased levels of integration of people with disabilities into community life. Greater efforts to end social isolation will be needed before disability ceases to result in the exclusion of some Americans from all the benefits that our society has to offer.

Despite substantial progress in enabling people to remain in the community, elderly Americans with disabilities are increasingly shunted off into nursing homes, where they often find themselves at the mercy of an industry badly in need of reform. In addition, a substantial number of people with mental retardation or developmental disabilities remain institutionalized, without the freedom to lead the lives they would choose. Institutional life is the antithesis of integration and full societal participation, and better ways must be found to foster continued residency in the community for the elderly with disabilities and for those of all ages with MR/DD. In particular, federal programs that pay for nursing home care, but not personal assistance services, often force those with disabilities into institutions, even though assisted living in the community would benefit the individuals, society at large, and the taxpayer.

Social integration is a lifelong process, beginning in school and extending through employment, family life, and participation in community activities. Children with disabilities are increasingly being integrated into mainstream educational settings, making them more likely to finish school and find jobs. Continued improvement in the proportion who spend all or most of their day in regular classes is still needed, as is greater accessibility of many school facilities (see next chapter). Employment should be the next avenue for integration, but, despite the possible improvements in job opportunities mentioned in the Employment chapter, labor force participation for people with disabilities remains low. And, although family support is often crucial in order for those with disabilities to live in the community, statistics indicate that those who acquire disabilities early in life may have less of an opportunity to form families. In all, the proportion of people with disabilities who live alone (many of them elderly) is twice as high as that of people without disabilities.

Myths and Facts

Myth: *Disability is purely a medical problem, to be treated by doctors and nurses in the hope of a cure.*

Fact: **Disability is largely a social phenomenon, best dealt with by enabling people with disabilities to lead independent lives.**

Myth: *People with disabilities are much more integrated into society than they were before.*

Fact: **There is little evidence of increased levels of participation by people with disabilities in social, cultural, and commercial activities over the past decade.**

Myth: *People with disabilities no longer live in institutions.*

Fact: **The number of people with disabilities living in institutions is larger than ever. Some 1.8 million Americans, almost all elderly, reside in nursing homes.**

Myth: *"Mainstreaming" of children with disabilities leads to classroom disruptions and lowered educational standards.*

Fact: **Teachers and parents agree that mainstream education is beneficial both to most students with disabilities and their non-disabled classmates.**

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Data Sources:

Data from the 1994 Harris poll on life satisfaction, social isolation, and activities engaged in, along with comparisons with the 1986 poll, come from: Leitman, R., Cooner, E., & Risher, P. (1994). *N.O.D/Harris Survey of Americans with Disabilities* (942003): Louis Harris and Associates, Inc., N.O.D.

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Data on mental disorders among nursing home residents, from the 1985 National Nursing Home Survey, come from: National Center for Health Statistics. (1991). *Mental Illness in Nursing Homes: United States, 1985* (Vital and Health Statistics 105): NCHS, U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

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Department of Education statistics come from: U.S. Department of Education. (1995). *Seventeenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act:* U.S. Department of Education. Additional statistics come from the *1995 Digest of Education Statistics.* Both documents are available on the Department of Education's Worldwide Web site: http://www.ed.gov/.

Results from the 1989 Harris survey of educators and parents are reported in: Louis Harris and Associates. (1989). *The ICD Survey III: A Report Card on Special Education* (874009): Louis Harris and Associates, Inc.

Barriers to Independence

Despite significant improvements resulting from the passage of the ADA, 24% of people with disabilities responding to a 1994 Harris poll reported that lack of access to public buildings was a problem for them. People with disabilities continue to face architectural, physical, and communication barriers that prevent or limit their access to office buildings, stores, theaters, restaurants, hotels, and private homes. Even when a ramp leads directly to the entrance, a wheelchair user might not be able to use a facility if there are no accessible parking spaces nearby or if the front doors are too heavy to open. An absence of Braille signs can prevent a blind person from locating the correct room, and a person with a hearing or speech impairment might be unable to enter because of a voice-only security system.

Barriers can sabotage the best efforts of people with disabilities to lead fully integrated lives. A flight of stairs can make it impossible for someone to leave his or her home. An unramped front step, lack of a nearby curb cut, or a narrow bathroom door will deter a wheelchair user from eating out at a particular restaurant or visiting a friend's home. In the absence of raised or Braille numbers on the buttons in an elevator, a blind receptionist might be excluded from a job in an office highrise.

Thus, removal of existing barriers, coupled with barrier-free design of new buildings, has become a principal focus of disability legislation, litigation, and activism. Only in the absence of such obstacles do people with disabilities have the freedom to go where they want, live where they wish, and become full participants in American society.

Inaccessibility of Public Establishments: A Continuing Problem

In 1993, the General Accounting Office polled people with disabilities, asking them about architectural and communication barriers they had encountered during the previous 6 months while visiting public establishments. The results, which indicate how often, on average, each type of barrier was encountered, show that barriers continue to limit the accessibility of stores, restaurants, theaters, offices, and hotels.

During that same year, GAO inspectors toured buildings in selected cities to investigate compliance with federal accessibility guidelines.

Barriers to entry are frequently encountered, according to the GAO survey, the most often being a door that is too heavy to open. Other common problems (cited *sometimes* or *often* by survey respondents) are lack of a handrail on a ramped path, doorknobs that are difficult to operate, a security system unusable by someone with a visual impairment, and a doorway too narrow for a wheelchair.

Communication barriers, which can prevent access just as effectively as a locked door, are among the problems most frequently cited by survey respondents. There is *often* insufficient availability of large-print, Braille, or cassette information (for example, museum brochures or transit schedules) and of sign language interpreters, when needed. Inadequate signage is also a common complaint, either lack of signs indicating the location of accessible features or too few Braille or raised-print signs. GAO's inspectors confirmed poor signage as a very significant problem, with 82% of buildings lacking signs pointing out accessible alternatives to stairways and a similar 82% lacking room signs in Braille and raised lettering.

Within public establishments, several access problems are mentioned as occurring *often*. Problems affecting wheelchair users include bathroom stalls too small to enter or too cramped for the door to be closed, aisles that are too narrow, service counters that are too high, restaurant tables with legs that get in the way, and segregated theater seating that prevents the wheelchair user from sitting with non-disabled friends. Elevators *often* lack audible signals for visually impaired users, and there is *often* no Braille sign beside the elevator entrance.

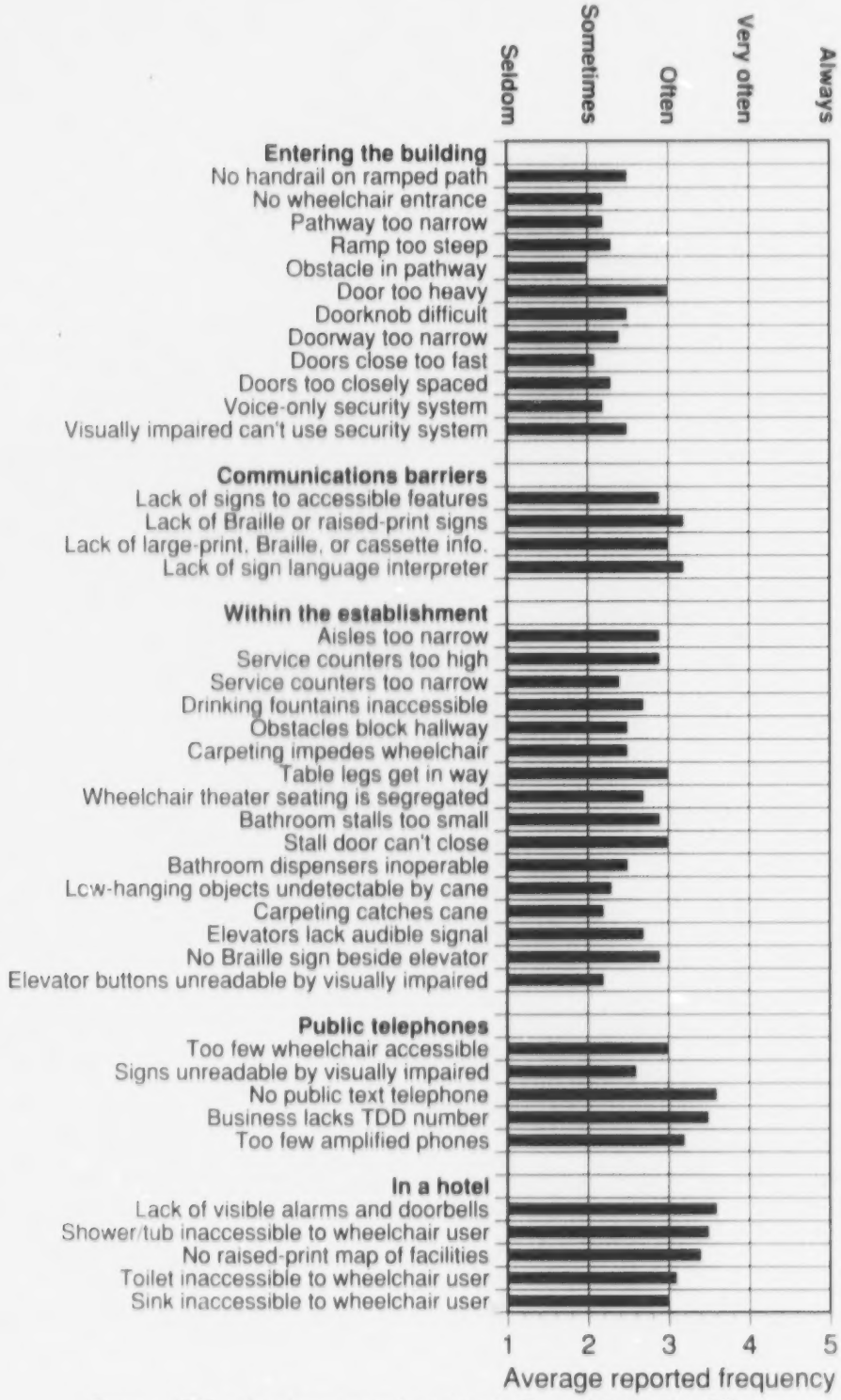
Lack of accessible public telephones is a major problem, according to the survey. There are *often* too few wheelchair-accessible phones, and visually impaired people frequently have difficulty reading the signs on pay phones. Deaf and hearing-impaired people report that there is *often* or *very often* no public text telephone or no public phone with amplification, nor do businesses they wish to contact have a TDD number.

The greatest level of reported problems involved hotel stays. The GAO's inspection teams confirmed these survey results, finding that 81% of inspected hotels lacked the required number of assistive devices for deaf people and 84% lacked the required number of wheelchair accessible rooms. Survey respondents cited several deficiencies as occurring *often* or *very often:* lack of devices to alert deaf guests of fire alarms, the phone ringing, or someone knocking at the door; showers and bathtubs inaccessible to wheelchair users; lack of raised-print maps of hotel locations for visually impaired guests; and toilets and sinks inaccessible to wheelchair users.

Recent Litigation Involving Barrier Removal

Violations of disability access requirements remain pervasive throughout the United States. Actual or threatened lawsuits by the Department of Justice and disability rights groups have highlighted continuing difficulties in many of the problem areas found in the GAO survey. In February 1996, the Justice Department sued the Days Inn hotel chain, charging that none of the 28 newly constructed hotels it had inspected met the accessibility standards of the ADA. The hotels lacked visual alarms to alert deaf guests to fires; wheelchair ramps had too-steep inclines, sloped sideways, or lacked handrails; bathrooms in "accessible"

Reported Access Barriers in Public Establishments



Source: 1993 national survey conducted by the General Accounting Office

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Key Points

- Accessibility of public facilities is a problem for 24% of Americans with disabilities.
- Most-often-cited accessibility problems include lack of Braille or raised-print signs and materials, too-narrow store aisles, absence of amplified and text telephones, and hotel rooms without wheelchair-accessible bathrooms, visible fire alarms for the deaf, and raised-print maps of escape routes for visually impaired guests.
- On both a national and local level, vigilance, political muscle, and legal actions are necessary to ensure that even new construction meets accessibility codes.
- A new building can be designed and built for accessibility at a tiny additional cost.
- Removal of existing barriers generally costs more, but it is often relatively inexpensive.
- In some areas, particularly inner cities, accessibility of the public schools is a major problem, preventing the effective education of children with disabilities.
- Only a tiny fraction of American homes are fully accessible, making it difficult for people with disabilities to find homes, to stay in their present residences when they experience disability, and to visit friends.
- New, multi-family housing must meet certain accessibility requirements, but current law is far from guaranteeing full accessibility of all new homes.

rooms lacked adequate maneuvering space; there were no signs in Braille or raised lettering; and parking was inaccessible or there was no wheelchair-accessible path between the parking lot and the hotel.

Inaccessibility of stores, restaurants, and theaters have resulted in many other legal actions. In a July 1995 agreement with several disability groups and the Department of Justice, Safeway promised to remove bollards from in front of its 800 supermarkets; the metal poles had been intended to deter theft of shopping carts, but also prevented people in wheelchairs from entering the stores. A DOJ review of 97 recently constructed or remodeled Lone Star restaurants found insufficient wheelchair-accessible parking and seating, inadequate ramps, and inaccessible bathrooms; a February 1995 agreement resulted in the correction of these deficiencies.

In an April 1996 settlement with disability groups and the DOJ, the United Artists chain of 400 movie theaters agreed to provide space for customers in wheelchairs at various locations within the theater, rather than only in the back row. They also promised to arrange seating so that those in wheelchairs could sit next to non-wheelchair-using friends and to install aisle seats with removable armrests, for wheelchair users wishing to transfer into regular seating.

In other recent settlements with the DOJ, Disney World agreed to provide sign language interpreters to patrons who are deaf and the Friendly's Restaurant chain agreed to remove access barriers throughout its operations. As the result of a court ruling, children with disabilities can no longer be excluded from participation in Little League baseball solely because of their disability. Litigation to enforce the ADA has also been brought against a number of other

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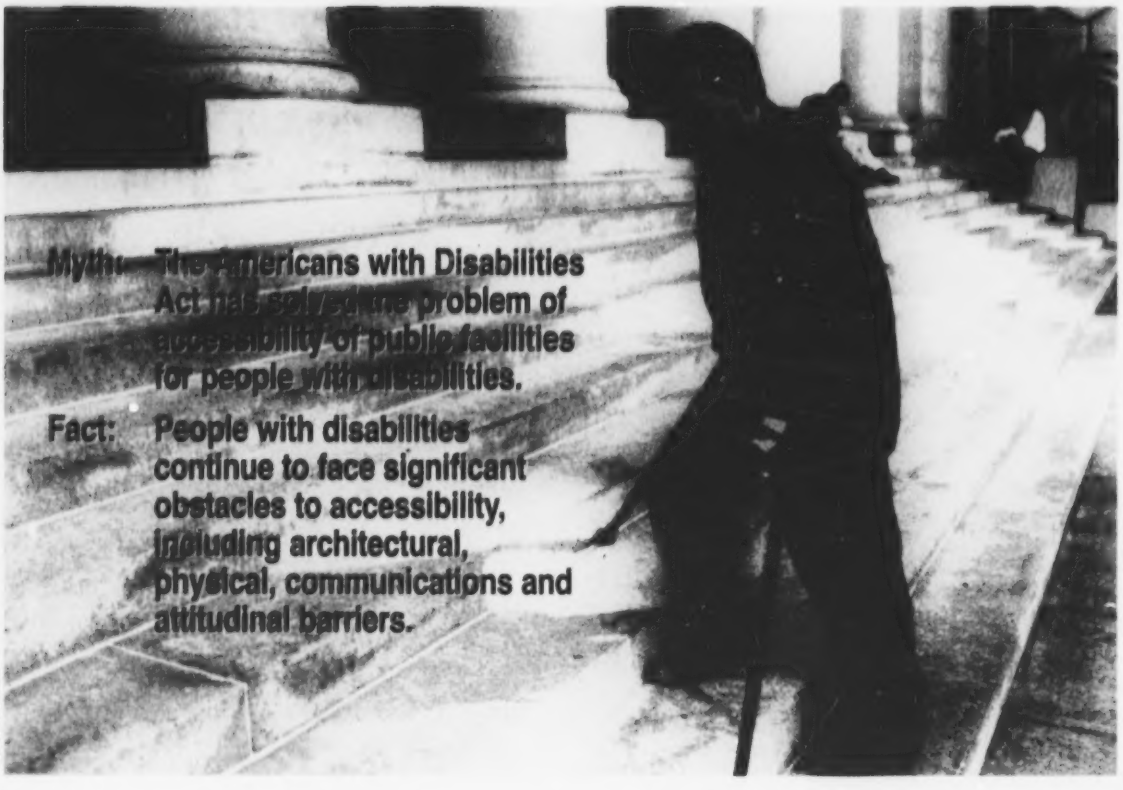
Myth: The Americans with Disabilities Act has solved the problem of accessibility of public facilities for people with disabilities.
Fact: People with disabilities continue to face significant obstacles to accessibility, including architectural, physical, communications and attitudinal barriers.

Photo: Will Lieber

large retailers and businesses, such as the Jack-in-the-Box restaurant chain, BP Gas Stations, Kindercare Learning Center, Macy's Department Stores, various car rental chains, and Holiday Inn Hotels.

Local Variations in Accessibility

The above-mentioned national chains were singled out in order to focus national attention on the widespread barriers that preclude access by people with disabilities. But disability groups have found no lack of local targets engaging in flagrant violations of the law:

The San Diego disability community recently won two major victories, one against municipal judges, who wanted their new courthouse exempt from state accessibility codes, and the other against a chain of parking lots that had failed to provide a sufficient number of accessible spaces. Elsewhere, legal battles are currently being waged against prominent restaurants that refuse to ramp their entrances; lawsuits have also cited the Washington, D.C. and Maui, Hawaii branches of the Planet Hollywood restaurant chain for forcing customers in wheelchairs to enter through dirty service elevators. Ironically, a recent *New Mobility* article on the Paralympics complained of a dearth of curb cuts in downtown Atlanta, suggesting legal action as a likely solution. And a suit has been filed against the city of San Francisco, charging that officials routinely grant exemptions to state accessibility codes, a pattern resulting in hundreds of new buildings in the city being inaccessible to wheelchair users.

Because enforcement of building codes is largely a local responsibility, the degree of accessibility of public facilities varies greatly

from community to community. Similarly, removal of barriers in streets and on sidewalks—for example, the installation of curb cuts at intersections—is a matter for municipal public works departments, whose priorities and resources depend on many local factors. In 1993, disability activists in Philadelphia won a victory when the courts held that resurfacing of streets constituted an alteration under the ADA, meaning that curb cuts must be installed at intersections whenever streets were resurfaced.

Cities and towns without highly visible disability communities are less likely to provide appropriate access to public facilities. Vigilance on the part of disability groups, possibly combined with selective lawsuits, is often the only means to ensure that laws are enforced on the local level and that barriers are removed.

The Low Cost of Barrier Removal

Including accessibility features into the design of a new building adds only a tiny fraction to the cost of construction. In building a new house, for example, construction costs increase by only an estimated 2% when it is made accessible. Some "universal design" features (such as lever-operated door handles that can be opened easily by those with limited manual dexterity) cost no more to install in a new building than the inaccessible features they replace (in this case, traditional doorknobs).

Because removing existing barriers can be more expensive, federal law imposes stricter standards on new construction than on existing structures, requiring the latter to meet accessibility guidelines only when "readily achievable" or when the building is being renovated. Business owners are therefore not forced to suffer undue financial hardship in order to meet current ADA requirements for accessibility.

Estimates of the typical costs to businesses of removing architectural and other access barriers are relatively low, so that most business owners have little excuse for not doing so. Figures from the Internal Revenue Service indicate that 12,728 small businesses (up to $1 million gross receipts or 30 full-time employees) made use of the Disabled Access Tax Credit for the 1993 tax year, receiving a total of $19,579,000 in credits. This credit applies to 50% of barrier-removal expenditures of between $250 and $10,250 made during the year. From these statistics, it is possible to estimate that, for small businesses removing access barriers during 1993, the average one-time expenditure was $3,327, *half of which was reimbursed by the federal government as a tax credit.* Considering only individually-owned businesses, the figure is even smaller—$2,535, or $1,392 after the tax rebate is applied.

The above expenditures include not only physical modifications to the premises, but also acquisition of text telephones, printing of Braille signs or large-print documents, or hiring of sign language interpreters. Although unusual circumstances may greatly increase the cost of barrier removal, the data make it difficult to accept claims of impoverishment by business owners who refuse to accommodate people with disabilities.

Pervasive Architectural Barriers in the Public Schools

Many of America's public school systems present formidable barriers to children with disabilities, despite federal law requiring school districts to provide an education to all students, regardless of disability. Newly constructed (after 1979) buildings must meet accessibility standards, according to Section 504 of the

Barrier-Free Design

What it means for a building to be accessible is often a matter of perspective. A business owner might declare her premises accessible if they meet the legal requirements contained in the ADA Access Guidelines or if they adhere to state or local building codes on accessibility. A person with a disability might consider his home accessible, on the other hand, if he has no trouble entering, exiting, or getting around, and if it contains no impediments to his safety or obstacles to his performing everyday household tasks. Such a definition would depend on the nature and severity of the disability, ranging from a flashing-light smoke alarm for a person with a hearing impairment to ramps, wide hallways, and so on for a wheelchair user.

On the whole, the architecture profession has been very slow to recognize the needs of people with disabilities. Rather than rethinking basic principles to enable people of all abilities to have full use of their homes and easy access to businesses, architects have by and large continued to design barrier-laden buildings, except when certain accessibility features are required by law or customer demand. Recently, however, some useful concepts relating to accessible design have emerged:

Adaptable design incorporates certain fundamental accessibility features and paves the way for others to be added later, if needed. A house might be designed with a ramped entrance, wide doors, and a spacious bathroom—features that would be much more costly to add in after the fact. There might be no grab bars in the bathroom, but the walls would be reinforced in case grab bars need to be installed later, at minimal cost. The kitchen might have cabinets below the counters, but these would be installed so that they could be removed relatively easily. The overall philosophy is one of contingency: If needed, accessibility can be improved without major renovation.

Universal design is a much more ambitious goal, one of usability by everyone, regardless of ability level. In addition to the standard accessibility features, universal design elements include lowered and touch-activated light switches, raised electrical outlets, height-adjustable shelves and rods in closets, lever-operated door mechanisms, and storage space within reach of people of any height. A universally designed house might have all its living space on one floor, a side-by-side refrigerator/freezer, and a bathtub faucet closer to the edge of the tub than the center. The emphasis is on simple, intuitive, flexible, and equitable use of space and equipment.

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Rehabilitation Act of 1973, while existing facilities must provide equal overall access to programs and activities, but are not specifically required to remove barriers in every building. The ADA also applies to public schools, imposing the same accessibility requirements.

There are no national statistics on the accessibility of public schools. In a 1989 Harris poll, however, 20% of parents of children in special education programs rated the accessibility of their school's physical facilities as "fair" or "poor"; educators reported "fair" or "poor" accessibility 21% of the time. Some 72% of educators said that the school or school district had removed architectural barriers or changed furniture to improve access; the proportion of suburban districts that had removed barriers (78%) was much higher than that of urban districts (61%), while small town (74%) and rural (73%) districts fell closer to the average.

Since that time, school districts have expended considerable sums of money on accessibility. A General Accounting Office report published in December, 1995 found that 53% of schools had removed at least some of the existing architectural barriers during the preceding 3 years, spending a total of $1.5 billion during that period. However, future spending on accessibility, estimated at $5.2 billion during the subsequent 3 years, was needed by 56% of schools. Only 26% of schools reported that no spending was needed. Thus, considerable work remains before all U.S. public schools are fully accessible to all children with disabilities.

Because school districts are under local control, and the age of facilities and the financial health of the system differ from one district to the next, there are significant geographical variations in accessibility. For example, in a decision resulting from a lawsuit brought by the Center for Independent Living in Berkeley, a federal court found "multiple, pervasive architectural barriers" in all of the hundred public schools in the Oakland, California district. And the GAO discovered that most schools in Chicago and New Orleans were inaccessible.

In general, their investigators found that schools in central cities were less likely to have spent money on accessibility than suburban schools, while schools in rural areas and small towns were the most likely to report that no spending on accessibility was needed. It is possible that districts in the last category are simply unaware of accessibility problems.

From both the Harris and GAO data, it would appear that central-city school districts, which are often financially hard-pressed, are less likely to remove barriers, perhaps providing only the most general accessibility to their programs and activities. The more wealthy, suburban school districts, on the other hand, seem to have been more vigilant in removing barriers, providing access to a greater number of facilities for students with disabilities.

Housing Accessibility

The vast majority of housing units in the United States lack features that would make them suitable for or readily adaptable to the requirements of people with disabilities. Data from the 1990 National Health Interview Survey indicate that only 2.9% of Americans live in homes with any kind of accessibility features, including ramps (0.9% of persons), extra-wide doors (0.7%), elevators or stair lifts (0.2%), handrails (1.4%), and raised toilets (0.5%).

But according to the same survey, the proportion of American families containing at least one member with a disability is 10 times as high—29.2%. And almost all families

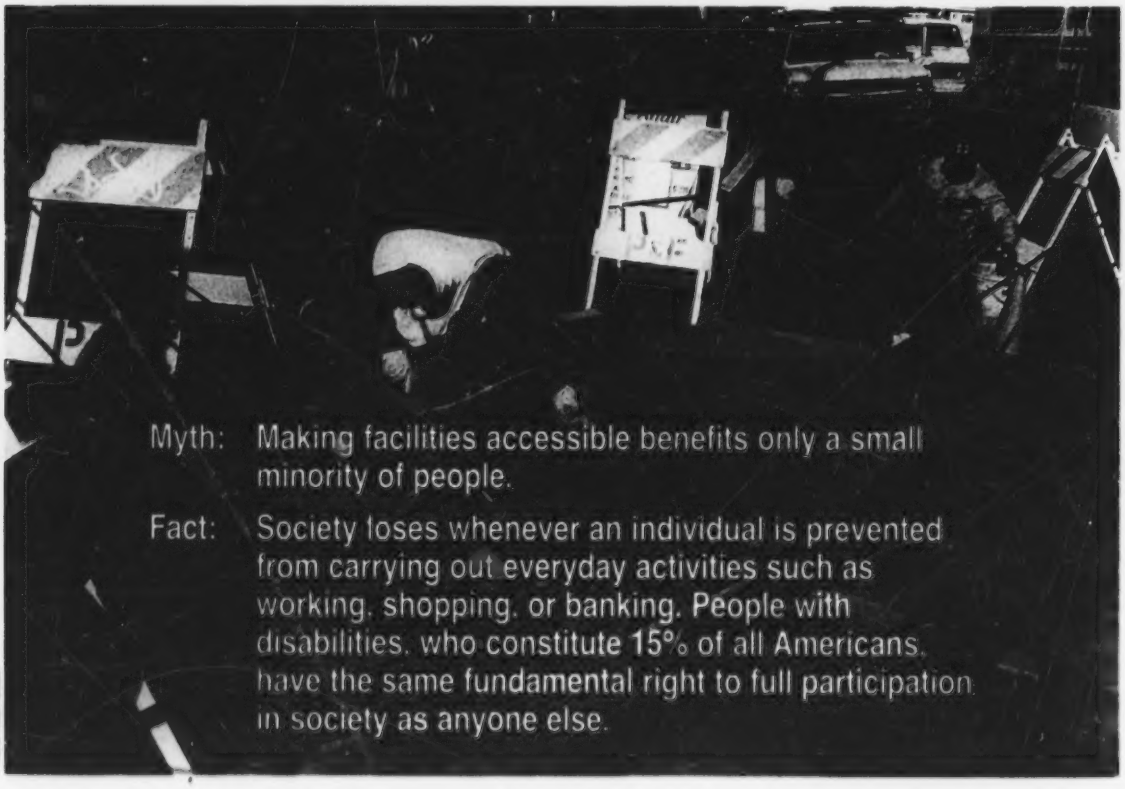
Myth: Making facilities accessible benefits only a small minority of people.
Fact: Society loses whenever an individual is prevented from carrying out everyday activities such as working, shopping, or banking. People with disabilities, who constitute 15% of all Americans, have the same fundamental right to full participation in society as anyone else.

Photo: Ken Stein

experience disability at some time, for example, as the older members become elderly. In an ideal world, a family in which a member acquires a mobility or sensory impairment would be able to remain intact and continue living in the dwelling they'd occupied before, which would either need no modification to accommodate the disability or require only simple alterations to meet the family's new needs.

Unfortunately, families experiencing disability often find that their existing homes are unsuitable and that renovations are difficult or costly. The ground-floor entrances and existing elevators that make barrier removal comparatively simple for businesses are often lacking in private houses and apartments. The family may be forced to disrupt their lives by moving to a new neighborhood or, worse, to exclude the member with a disability who can no longer function in the household environment. As a result of a shortage of accessible housing in many areas, families and individuals with disabilities also find it difficult to find suitable houses and apartments to rent or buy.

The 1988 Fair Housing Amendments Act includes protection against housing discrimination on the basis of disability. It includes provisions preventing owners of most multi-unit buildings, as well as certain single-family houses, from refusing to rent or sell to people with disabilities. It also requires that new multi-unit housing—any building with 4 or more units constructed or first occupied after March 13, 1991—have certain accessibility features. These include at least one building entrance on an accessible route, accessible public and common areas, and in certain units (ground floor units in all buildings and all units in buildings

with elevators), doors and hallways wide enough to accommodate wheelchairs, accessible switches and controls, sufficient space in the kitchen and bathroom for a wheelchair to maneuver, and reinforcement of bathroom walls to allow for installation of grab bars.

The required features do not constitute full accessibility, but are intended to make the building easily adaptable in case of occupancy by persons with disabilities. This provision may still place a significant burden on the occupant, however, for making the necessary modifications when needed. The Act contains no provision to compel landlords—whether of newly constructed buildings or old—to make residences suitable for occupancy by tenants with disabilities. It only prohibits them from preventing tenants from making reasonable modifications *at their own expense* to make their unit habitable.

The Fair Housing law may result in some gradual increase in housing units that can be made accessible to people with disabilities. However, it will do next to nothing to increase the number of fully accessible apartments and will have no effect whatsoever on the accessibility of single-family homes. Thus, in spite of the low cost of many accessibility features, fully accessible housing for people with disabilities continues to be in very short supply, and new houses continue to be built lacking even the most basic features that would simplify their eventual conversion to accessibility when needed.

Conclusions

Inaccessibility of public establishments remains a significant problem for people with disabilities, one that often excludes them from everyday activities like shopping, dining out, going to the movies, or staying in a hotel. Many business and property owners have been slow to remove barriers, despite the several years that have passed since the enactment of the ADA. Although they may deceive themselves with claims that their facilities are not used by people with disabilities, or that no complaints have been issued against them, they must realize that even a single step can be a powerful deterrent. They must increase their awareness of the needs of actual and potential patrons who have disabilities, along with their willingness to accommodate those needs. Removing barriers can be inexpensive, can bring in new customers with disabilities, and can alleviate the risk of costly lawsuits.

It is particularly astonishing, not to mention economically unwise, that buildings continue to be designed and built without adequate consideration of the requirements of people with mobility and sensory impairments. The law makes clear that new construction must be designed for accessibility, and planning departments and building inspectors must enforce codes to guarantee that no new barriers are erected to the independence of people with disabilities.

Tax credits help to subsidize the cost of removing barriers in businesses, but there is no equivalent subsidy for making private homes more accessible. Most families and individuals confront disability at one time or another, and they are often forced to move—or to send a member with a disability into an institution—when their homes lack accessibility features. If more houses and apartments were made accessible from the start, and if government assistance were readily available to help families improve the accessibility of their homes, families could stay in their homes, rather than suffering the tremendous disruption that moving entails.

Myths and Facts

Myth: *The Americans with Disabilities Act has solved the problem of accessibility of public facilities for people with disabilities.*

Fact: **People with disabilities continue to face significant obstacles to accessibility, including architectural and physical barriers, communications barriers, and attitudinal barriers.**

Myth: *Making facilities accessible benefits only a small minority of people.*

Fact: **Society loses whenever an individual is prevented from leaving home, from traveling to work, from carrying out everyday activities like shopping, going to the bank, or eating in a restaurant. People with disabilities—15% of all Americans—have the same fundamental right to independence, to full participation in society, as anyone else.**

Myth: *Businesses can go bankrupt when forced to remove architectural barriers.*

Fact: **Barriers must be removed only when the removal is "readily achievable"; the cost is often modest and is partially reimbursed through a tax credit. Newly constructed or renovated facilities can be made accessible by design at a fraction of the cost of removing existing barriers. People with disabilities also constitute a profitable market for many businesses.**

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Data Sources:

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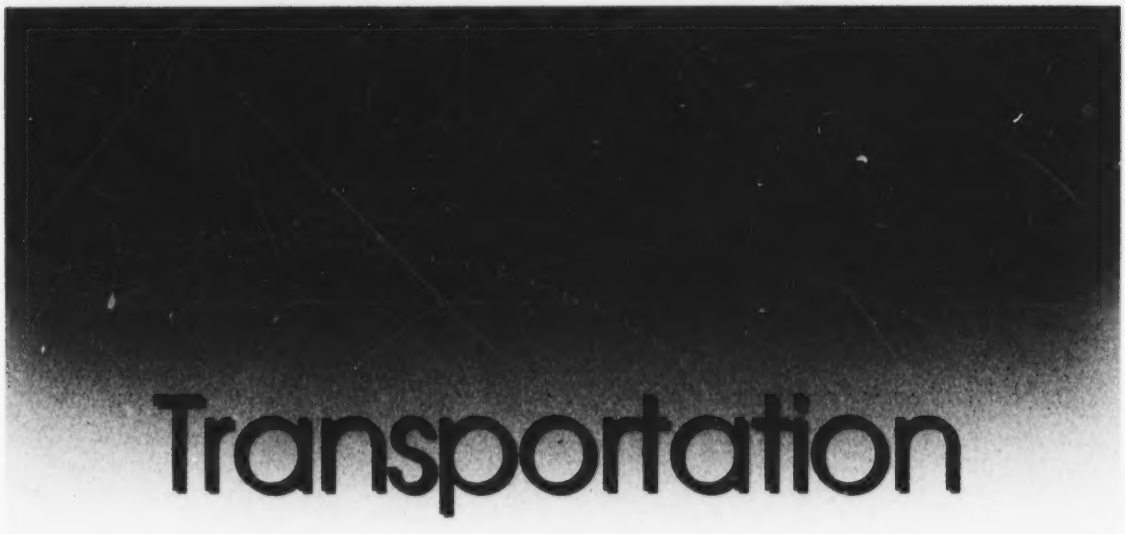


Transportation

In 1955, Rosa Parks refused to move to the back of a Montgomery, Alabama city bus, asserting that she, an African American, had as much right to sit in the front as any white person. Her arrest, and the protests that followed, sparked a broadening of the Civil Rights movement, which would eventually result in legal guarantees of equal treatment for all Americans. Four decades later, however, people with disabilities still receive decidedly second-class transportation services, services that are critical to leading full, independent lives.

Few wheelchair users would even have dreamt of trying to use public transportation in 1955. Even if they could have been lifted up onto the bus or carried down the stairs to the subway platform, their wheelchair probably would not have fit through the door or been able to navigate the narrow aisles.

Thirty years later, in 1985, 76% of the buses used for public transit in the U.S. were still inaccessible to wheelchair users, despite greatly improved technology and an increased awareness of the needs of people with disabilities. Since then, federal legislation has brought about improvements, and today, the Department of Transportation estimates that 55 to 60% of public transit buses are equipped with wheelchair lifts. These figures are misleading, however, because lifts are too often out of order and drivers too often ignorant of how to operate them.

Thus, despite some progress, people in wheelchairs are often left behind, and those who are blind or hearing impaired left to fend for themselves without the audible or visible information they need to travel safely and effectively. In a 1994 Harris poll, 24% of people with disabilities who were not working (or only working part time) cited a lack of affordable, convenient, accessible public transit as an important reason that they could not take a job.

Ready access to both public and private transportation is essential in order for people with disabilities to lead full, independent lives. They must be able to travel to and from work, shopping, and leisure activities, visit friends, take vacations, and go on business trips. Lack of suitable transportation can severely constrain one's daily life. Unless she owns a lift-equipped

car or van, a wheelchair user cannot accept an offered job if there are no accessible buses, vans, or taxis to take her there. Without such a job, she will be forced to use public disability programs as her main means of support, and to forego the most basic step in social integration.

Public Transit: Many Problems Remain

Depending on political, financial, and practical considerations, municipal and regional transit agencies can make transit accessibility a high priority, grudgingly accede to the requirements of the ADA, or ignore federal accessibility mandates entirely until forced to comply in court. Some transit districts have not even begun the ADA-mandated planning phase for improving their system's accessibility, let alone made any actual improvements. Thus, the ability of people with disabilities to have full use of public transit systems varies considerably from one city to the next, from one region to another.

Bus Service

San Francisco is an example of a city with a variety of transit alternatives, providing widely different levels of access, which illustrate the difficulties people with difficulties face in trying to use urban transportation systems. Because ADA regulations apply primarily to newly purchased equipment and newly constructed stations, 83% of the city's 346 electric (trolley) buses lack wheelchair lifts. Since these vehicles stay in service for an average of 20 years, and since existing vehicles are not required to be retrofitted with lifts, it may be decades before all of the agency's bus lines are accessible to wheelchair users. In contrast, all of the city's 455 diesel buses are equipped with lifts and capable of "kneeling" to allow people with limited climbing ability to board and exit. In all, only about half of the city's bus routes are listed as "wheelchair accessible."

Other cities, such as Seattle and New York, can claim full accessibility of their bus routes. These optimistic statistics, however, do not reflect reality for wheelchair users, who frequently report malfunctioning lifts and drivers not properly trained to operate them. In his memoir, *Moving Violations*, journalist John Hockenberry complains that New York City buses that are newly put into service invariably have non-functioning lifts; other buses have lifts that leave the passenger stuck in mid-flight or for which the driver has no key. In Philadelphia, disability advocates filed an ADA suit against the regional transit agency, SEPTA, for failing to keep wheelchair lifts on buses operational. SEPTA recently entered into a settlement containing financial penalties should it fail to reach a 75% compliance rate.

It is astounding to note that, while buses are kept out of service when they have a faulty turn signal or windshield wiper, an inoperable wheelchair lift is not considered serious enough to keep a bus out of service while it is repaired. Often, lifts are not even tested along with all other equipment at the beginning of the route.

Worse still are drivers who refuse to pick up passengers with disabilities. Wheelchair users are sometimes left at the street corner as the bus speeds by, the driver not even bothering to stop and explain the problem. This appalling degree of disregard for the dignity of those with disabilities is reminiscent of the treatment of African Americans in the South before public transit was integrated.

Visually impaired people also experience problems in riding the country's municipal bus fleet. Drivers are instructed to call out key stops to help orient blind riders, who may

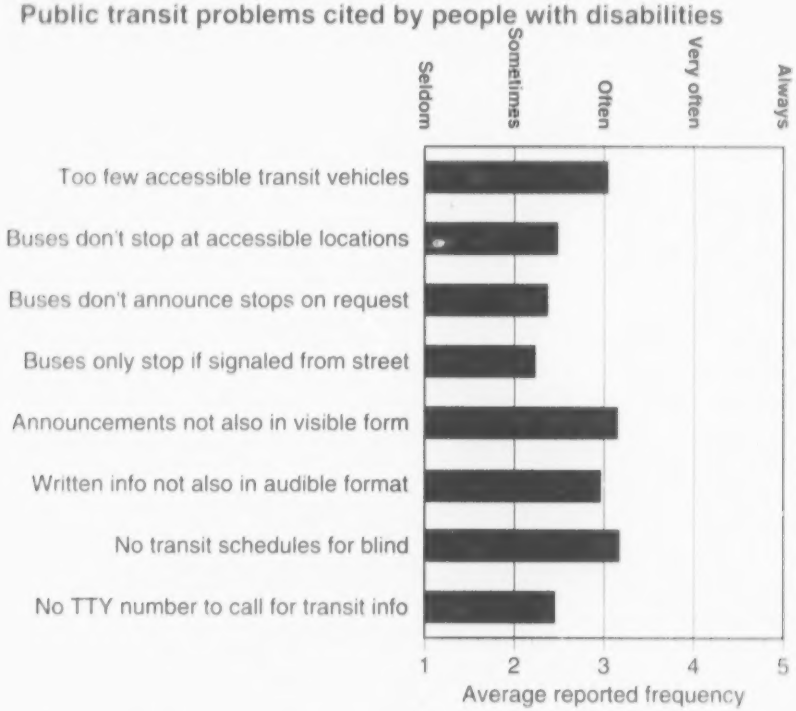
otherwise be unable to navigate the city's public transit maze. But in San Francisco, at least, officials acknowledge that drivers do not always do so, a situation that resulted in a recent lawsuit by riders with disabilities. In settling the suit, the transit agency agreed to enforce compliance with its stop-calling policy, as well as to better safeguard platform edges to protect the safety of visually impaired transit users. In Philadelphia, SEPTA has also been sued for failure to call out stops for riders with visual impairments.

Light Rail and Rapid Rail

In addition to its buses, San Francisco has light rail and rapid rail systems. The light rail, operating as a subway in the downtown area and as streetcars elsewhere, is subject to the ADA requirement of wheelchair access only at "key stations." All of San Francisco's 9 underground stations can be reached by elevator (when they are working), and the platforms are level with the entrance to the cars. Above ground, however, access is greatly limited. In 1994, there were wheelchair platforms at only 10 out of a total of 94 above-ground stops. In 1995, plans were announced to make 15 additional stops accessible, for a total of 27% of all above-ground stops. Construction has still not been completed, however, despite the ADA requirement that "key stations" be made accessible by July, 1993.

At least one neighborhood group resisted a planned wheelchair ramp in their area on "aesthetic" grounds. The attitude of the press and many residents seems to be that wheelchair access is a little-used luxury hardly worth the expense, but this is a myth. The city's transit

Public transit problems cited by people with disabilities



Source: 1993 national survey conducted by the General Accounting Office

ADA Requirements for Public Transit

Vehicles:

- Newly purchased buses, subway cars, light rail vehicles, etc., must be "readily accessible."
- Vehicles remanufactured so as to extend their usable lives by 5 years or more must be accessible, "to the maximum extent feasible."
- For existing multi-car train, rapid rail, and light rail systems, at least one car must be accessible.
- When public agencies offer "demand responsive" transportation services, newly purchased vehicles must be accessible, unless an equivalent service is provided for persons with disabilities.

Facilities:

- All newly constructed transit facilities, such as subway and bus stations, must be readily accessible to persons with disabilities.
- Existing "key stations" in rapid and light rail systems must be made accessible.
- When alterations are performed on transit facilities, altered portions must be made accessible "to the maximum extent feasible."
- Except when structural alterations would be required, existing facilities must operate so that, "when viewed in the entirety, the program or activity is readily accessible to and usable by individuals with disabilities."

agency estimates that existing lifts and ramps were used 43,000 times during 1994. And in New York, increasingly accessible buses have resulted in a doubling of ridership by wheelchair users in two years.

Nationally, Department of Transportation figures indicate that 64% of the 700 identified "key stations" are at least partially accessible to wheelchair and walker users, while only 21% are fully accessible to people with mobility and sensory impairments.

On BART, a regional Bay Area rapid rail system similar to MARTA in Atlanta and the Washington Metro, elevators are supposed to provide access to all its stations, whether above- or below-ground, and the platforms are supposed to be level with the car floors.

Again, the appearance of accessibility is misleading. Elevators, which are too small for many wheelchairs and generally filthy, are often out of service. Information posted and given out over the phone is often inaccurate, causing wheelchair users to arrive at the station only to learn that the elevator is not working. Designated space for wheelchairs is provided only on a limited number of cars; otherwise, wheelchairs users are told to position themselves in the door well area, where they may find themselves in the way or crowded by other passengers waiting to exit the train. These and other problems have prompted a recent lawsuit by disability activists against BART, citing neglect of elevators, too-narrow fare gates, too-wide gaps between cars and the platform, lack of accessible ticket vending and collection equipment, and failure to give passengers with disabilities adequate time to board and exit the train. Similar complaints have been reported about malfunctioning elevators in the MARTA system, which also claims full accessibility.

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The New York subway system can make no claim of access. Only 6% of its 490 stations meet accessibility guidelines. These 28 stations amount to only one-quarter of the "key stations" required under federal and state laws. The rest of the system is completely inaccessible to wheelchair users. Most riders, especially those who transfer from one line to another, must negotiate a maze of stairways to get to their destination. Thus, people with any degree of mobility impairment find the subway difficult to use, if not impossible.

Other problems affect subway riders with visual impairments: While a flashing sign alerts sighted BART passengers to the impending arrival of a train and indicates its destination, no equivalent announcement is routinely made to let visually impaired passengers know where the train is heading. Instead, train operators are instructed to announce the destination "when they see a person with a visual impairment waiting at the platform," according to a BART brochure. How the train's lone operator is supposed to identify such people is not specified; visual impairments may not be readily apparent up close, let alone across the ten car-length distance from the front of the train to the back.

Paratransit

The ADA directs public transit agencies to provide so-called paratransit services to people with disabilities who cannot fully use regular transit services. Paratransit is meant as an alternative to inaccessible and too-distant transit routes—special buses, vans, or taxi service that might take riders door-to-door, drop them off or pick them up at a central location, or connect them with accessible transit services. The Department of Transportation estimates that 75% of the nation's public transit systems are in compliance with the ADA's paratransit requirements.

In San Francisco, the 10,000 people registered as eligible for paratransit made use of the service 917,000 times in 1995. Three modes of transportation are offered: a heavily subsidized taxi service (including a small number of ramped taxis), group vans with or without lifts, and door-to-door individual lift vans. Other cities offer similar services, but ramped taxis are still relatively uncommon.

Although the service is heavily used, it has several features that make it less than ideal. There is a long waiting list for eligibility for the service; someone new to the area or with a newly acquired disability must wait approximately 9 months before they can receive paratransit services. The service can be expensive, with a lift van costing $20 per ride, while subsidized taxi service is limited to $100 worth of travel per month. And some restrictions on the use of the service greatly reduce its flexibility and convenience. For example, a 24-hour advance reservation is required, meaning that all travel must be planned in advance, and a person with a disability is not guaranteed that space will be available for any non-disabled friends (apart from an attendant) he wishes to accompany him.

Local policies do vary, and some other cities offer services that are much more restricted. For example, in New Haven, Connecticut, paratransit must be reserved two weeks in advance for each use. Thus, a person wishing to commute to work each day by lift van must call every day, two weeks ahead, sometimes waiting on hold for 20 minutes before the reservation can be made. It is clear that some municipalities view paratransit as a service to be used only on

ADA Requirements for Intercity and Commuter Rail Services

Trains:

- At least one passenger car per train must be "readily accessible."
- All newly purchased passenger cars must be accessible.
- Passenger cars remanufactured so as to extend their usable lives by 10 years or more must be accessible, "to the maximum extent feasible."

Stations:

- Newly constructed stations must be accessible.
- Existing "key stations" on commuter rail lines must be made accessible.
- All intercity rail stations must be made accessible "as soon as practicable," but not later than 2010.
- When alterations are performed on stations, altered portions must be made accessible "to the maximum extent feasible."

special occasions—for example, to travel to and from a doctor's appointment—rather than as an essential substitute for unusable public transit.

A final disadvantage of paratransit is that it is a segregated service, at best "separate but equal" to ordinary public transit. Heavy reliance on paratransit runs directly counter to the goal of full integration of people with disabilities into the mainstream of society.

Intercity and Commuter Rail Service

The ADA imposes requirements on intercity and commuter rail systems that are similar to those for public transit services, with newly purchased cars and newly constructed stations, as well as existing "key stations" on commuter lines, required to be accessible to people with disabilities. Alternative "paratransit" services are not required, however, and only passenger cars undergoing major renovation must be made accessible.

Historically, rail carriers have been no more hospitable to people with disabilities than public transit systems. A 1982 GAO survey found that nearly three-fourths of urban rail stations were inaccessible to wheelchair users. Although that situation has improved (more than half of the stations on Amtrak's Northeast Corridor are now designated as accessible), equal access to train travel will be a long time coming. The ADA gives the responsible agencies 20 years—until the year 2010!—to make every station in the country fully accessible.

The ADA required that, by July 1995, at least one passenger car on every intercity and commuter train be wheelchair accessible. Nevertheless, Amtrak advises passengers using wheelchairs to call to verify the accessibility of the particular train they wish to ride on. Thus, despite the law, and even when the

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starting and ending stations are accessible, a wheelchair user is not guaranteed passage from one to the other.

For visually impaired passengers, Amtrak offers to call out stations "on request." This is another practice that requires people with disabilities to specially identify themselves to train personnel. Like bus drivers, conductors should call out stops as a matter of course, not only when aware of passengers who make their impairments known.

Commuter rail systems also provide varying levels of accessibility. California's CalTrain system only recently began to provide any degree of wheelchair access to its trains. In the absence of fully accessible cars, it offers portable wheelchair lifts to raise riders to train level. Because only 2 spaces for wheelchairs are provided on each train, and because work on station ramps and curb cuts has only begun, full accessibility is a long way off.

Intercity Bus Service

People with physical disabilities who live in rural areas and smaller cities may have no access to transportation whatsoever. In these areas, privately operated intercity buses are often the only means of public transportation. Although the ADA does impose significant requirements on private transportation providers, it makes an exception for intercity "over-the-road" buses, directing the Department of Transportation to issue accessibility regulations for such buses, but prohibiting them from requiring any structural modifications to the buses to allow wheelchair access.

Greyhound, the main operator of intercity buses in the United States, lobbied Congress to make this exception. Over seven years following the passage of the ADA, no progress has been made on this issue. The Department of Transportation has never issued the accessibility regulations for over-the-road buses that were called for under the ADA within a year after its enactment. Greyhound has taken no steps to provide wheelchair lifts or ramps for its buses, citing financial reasons. Intercity bus travel therefore remains the only mode of transportation completely off-limits to wheelchair users.

Air Travel: Often a Nightmare

Whether traveling on business, vacation, or to visit family and friends, people with disabilities make heavy use of airlines and air travel facilities. Often there is no alternative, since disabilities sometimes prevent those who have them from driving or from taking long road trips. United Airlines estimates that, depending on the level of traffic, between 7,000 and 15,000 people with mobility impairments pass through its facilities in Chicago's O'Hare Airport *every day*. Some of these passengers use wheelchairs routinely, while others may have less severe mobility limitations that nonetheless prevent them from walking the considerable distance to or from their gate.

Air travel is often a nightmare for those with disabilities. Federal regulations regarding accessibility of air travel originate not in the ADA but in an earlier, less stringent law, the Air Carrier Access Act of 1986. The Act provides no guarantee of equal access for people with disabilities and allows for no injunctive relief in court, only administrative relief. Because of these inadequacies, airlines are permitted to treat access for people with disabilities as an afterthought: They continue to use stairways to board small planes, making them completely inaccessible to people with mobility impairments, and inaccessible restrooms and narrow

Key Points

- Nationally, 40 to 45% of buses used by public transit systems have no wheelchair lifts.
- Although many transit systems claim full accessibility for some or all of their bus routes, problems with equipment, lack of training, and poor driver attitudes can greatly reduce actual accessibility by passengers with mobility and sensory impairments.
- Transit agencies have often been slow to comply with the ADA, doing so only under pressure of legal action.
- When transit systems are made accessible, people with disabilities use them.
- Although accessibility of intercity and commuter trains and stations has improved, full accessibility is far from reality.
- Due to government inaction and corporate stonewalling, intercity bus service remains completely inaccessible to wheelchair users.
- Airline travel is a significant problem for many people with disabilities, who have little legal recourse in case of inadequate treatment.
- Public facilities often lack adequate and appropriate parking spaces for people with disabilities.

aisles on planes of all sizes make independence an impossibility for many people limited in mobility.

People who know they cannot get to the bathroom on a long flight often dehydrate themselves beforehand to obviate the need, a practice that can lead to other health problems. Rough, rude, tardy, or otherwise inappropriate treatment at the hands of airline personnel is another very common complaint.

In an informal survey on air travel experiences conducted by the Paralysis Society of America, the most frequent complaints—from more than half of those responding—focused on attitudes, in particular rudeness or non-responsiveness. Specific problems mentioned were uncooperative flight attendants, including humiliation by flight personnel, refusal to stow the passenger's wheelchair in the cabin, failure of personnel to speak directly to the passenger, refusal to retrieve needed equipment in-flight, inappropriate treatment by security guards, long waits to disembark from the plane, and refusal to allow a passenger with a disability to travel without an attendant. Recent newspaper accounts have reported cases of airline personnel refusing to board people with AIDS or with severe physical disabilities, out of ignorance of the person's condition and abilities or out of a belief that crew members or other passengers might be inconvenienced.

The next most common problem cited in the PSA survey involved lack of knowledge and inadequate training of airline personnel. Passengers have had their wheelchairs and other equipment damaged, have been hand-carried down steps, and have not received transfer assistance when needed. Boarding and seating problems are also mentioned often,

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including lack of needed aisle seats and removable armrests and absence of a jetway to allow wheelchair boarding. Because existing facilities need be made fully accessible only when undergoing renovations, inaccessibility of airports is also a common complaint.

Privately Owned Ground Transportation

Travel to and from the airport can also be difficult for people with physical disabilities. Door-to-door airport shuttle vans, which take people from the airport directly to their home or hotel, are covered under the ADA's regulations for privately owned transportation providers. Because these requirements are more lenient than those for publicly run services, accessibility has lagged behind. At many airports, there are no accessible shuttles, and wheelchair users are forced to hire a special lift van, at considerable expense. Elsewhere, the number of accessible shuttles is small: The operator of the service at the Dallas/Fort Worth airport maintains only one wheelchair-accessible van; a wheelchair user must call to reserve it 24 hours in advance of her arrival at the airport, while a non-disabled person can simply walk up to any waiting van and be taken directly to her destination. The only alternative is a special lift van service, at four times the cost.

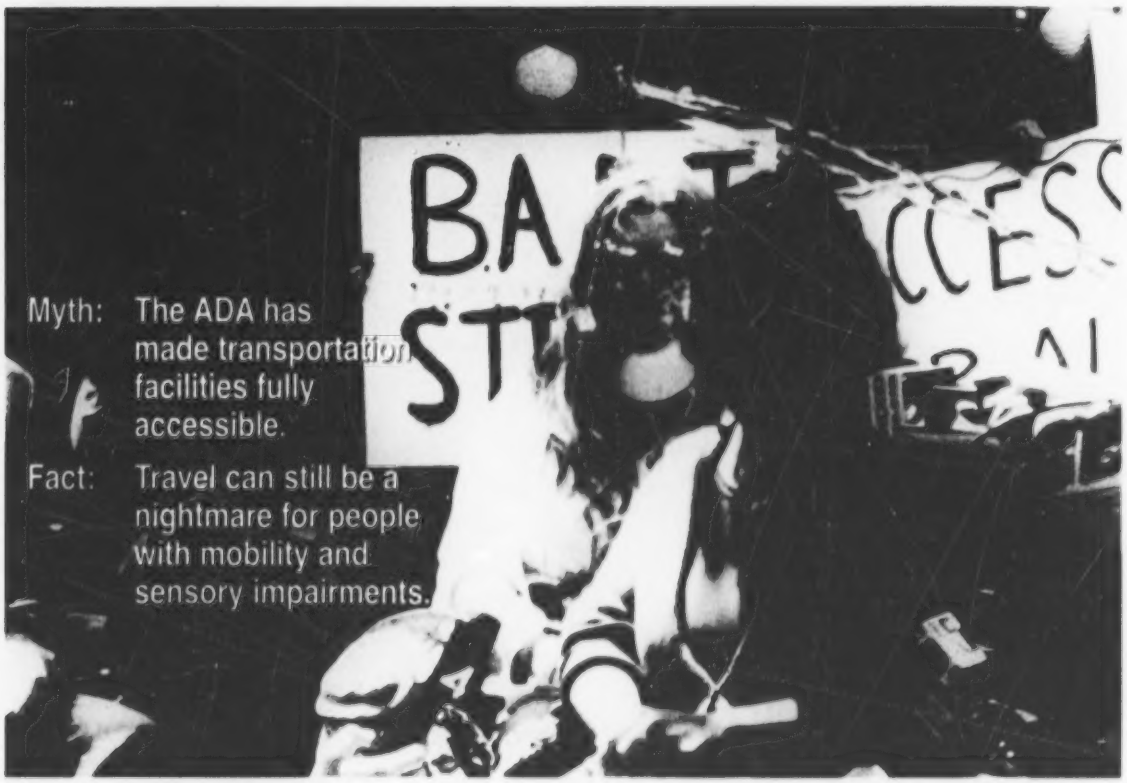
Complaints indicate that drivers often lack the proper training to operate the lifts; in such cases, the service can be useless or even hazardous. After arriving at the Honolulu airport, a wheelchair user eventually managed to board the special bus, but was not properly strapped into place, resulting in a harrowing ride into town, with the chair rolling and sliding around inside the vehicle.

Renting a private car is an option for some people with mobility impairments, but this can also prove difficult. Cars specially equipped with hand controls, so that a person with limited leg function can operate the gas and brake pedals, are not always available or may be available only on larger, more expensive vehicles. Again, considerable advance notice is generally required.

Furthermore, rental agencies may not be willing to conduct business with a person with a disability who cannot drive, even when he is accompanied by an attendant who does drive. A recent settlement between the Justice Department and Avis addressed this issue, with Avis agreeing to change its policy to allow non-driving persons with disabilities to maintain financial responsibility for a rented vehicle driven by another person. As part of this agreement, Avis allows people unable to work due to a disability to use non-employment related income as proof of financial responsibility in lieu of credit cards.

Accessible Parking

In a national survey conducted in 1993 by the General Accounting Office, people with disabilities reported that they often drove to public establishments only to find that there were not enough handicapped-designated parking spaces, that the aisle between spaces was too narrow, or that the slope was too steep (average reported frequencies are 2.7 for each of these problems, with 2.0 corresponding to "sometimes" and 3.0 corresponding to "often"). At the same time, GAO inspectors found that 38% of facilities they visited lacked the number of accessible spaces required under ADA guidelines and that spaces and aisles were not wide enough 57% of the time. An astounding 88% of parking lots lacked the required number of


Myth: The ADA has made transportation facilities fully accessible.
Fact: Travel can still be a nightmare for people with mobility and sensory impairments.

spaces designated as "van accessible."

Even when the ADA accessibility guidelines are followed, there is no guarantee that a person with a mobility impairment will be able to park. Smaller parking lots are required to have at least 4% of their parking spaces designated as accessible, a proportion barely adequate for the approximately 5% of Americans identified in the Survey of Income and Program Participation as having severe mobility limitations. The guidelines require larger lots to have an even smaller fraction of accessible spaces: those with between 400 and 1000 spaces must have 2% accessible, while the largest lots need have only 1% accessibility. Since 3.5% of the population uses a wheelchair, cane, walker, or crutches, this proportion is clearly inadequate. And because only one of every eight "accessible" spaces must be designated as "van accessible," the 0.9% of Americans who use wheelchairs are even further limited in their ability to find usable parking.

Conclusions

During the past decade, federal legislation has required public transit systems, passenger train services, airlines, and privately operated ground transportation providers to upgrade their facilities for people with disabilities. Although progress has been made, the results are uneven. In some areas, public transit systems are conveniently usable by most people with disabilities. In other cities and towns, however, compliance with the law has been slow and sometimes non-existent. And even when transit agencies and transportation companies do comply with the law, the results are

often inadequate to guarantee equal access, so that, for example, a person in a wheelchair could simply roll up to any city bus and board just as easily as someone boarding on foot. More stringent enforcement of the law is clearly needed in many locations.

Education is a key missing element. Even when buses, trains, and airplanes are accessible on paper, poor attitudes and inadequate training can prevent the use of these facilities by people with disabilities. Some bus drivers continue to leave people sitting in wheelchairs at the curb rather than spend a moment helping them on board. Others don't test the operability of the lift before starting their route, sending the bus in for repairs only if it malfunctions. And there are drivers who routinely fail to call out stops, even when they know that a blind person is on board. Rapid transit officials see the elevators that allow people in wheelchairs to board as an optional service, rather than a necessity. And airline personnel routinely mistreat people with disabilities, whether out of ignorance, impatience, or prejudice. Better awareness and training are necessary to bring about improvements in all these areas.

Stronger legislation is particularly needed in the area of air travel. Existing law provides no right of equal access and little opportunity for legal recourse. Poor treatment of people with disabilities by airlines has been the result, and it is likely that only new laws will cause policies to change and airplanes and air facilities to become more accessible. Intercity bus service is another area that is likely to require new legislation before any real progress is made in rectifying the current, woefully inadequate situation. Finally, accessibility guidelines for the number and width of parking spaces at public establishments must be both enforced and enhanced, in order to allow people with disabilities a fair opportunity to use these facilities.

Myths and Facts

Myth: *The Americans with Disabilities Act has made transportation facilities fully accessible.*

Fact: **Getting from place to place can still be a nightmare for people with disabilities.**

Myth: *People with disabilities don't use public transit, so accessibility is unimportant.*

Fact: **When transportation systems are made accessible, ridership by people with disabilities increases dramatically.**

Myth: *Wheelchairs provided at airports make air travel a breeze for people limited in mobility.*

Fact: **Air travel is difficult for many people with disabilities, due to inaccessible restrooms and terminals, poor treatment by airline personnel, and improper handling of wheelchairs and other equipment.**

Myth: *People with disabilities can use paratransit, and therefore don't have to rely on regular transit services.*

Fact: **Paratransit is an inadequate substitute for regular public transit. It is inconvenient, requiring an advance reservation for each use, and it enforces segregation of people with disabilities.**

Myth: *Too many parking spaces are reserved for people with disabilities.*

Fact: **Especially in larger parking lots, the required nmber of accessible parking spaces is inadequate to meet the demand.**

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Data Sources:

National data on transit accessibility were obtained from the U.S. Department of Transportation.

Data on transportation problems from the 1994 Harris poll come from: Leitman, R., Cooner, E., & Risher, P. (1994). *N.O.D./Harris Survey of Americans with Disabilities* (942003): Louis Harris and Associates, Inc., N.O.D.

Results on public transit and parking problems from the 1993 GAO survey are published in: U.S. General Accounting Office. (1994). *Americans with Disabilities Act: Effects of the Law on Access to Goods and Services* (GAO/PEMD-94-14): General Accounting Office.

Preliminary results from an ongoing survey on air passenger experiences were obtained from the Paralysis Society of America.

Data on mobility impairment from the 1994–95 Survey of Income and Program Participation are derived from unpublished tabulations provided by John M. McNeil, U.S. Bureau of the Census.

Conclusions

Landmark civil rights legislation has brought about a far greater awareness of the problems faced by the 15% of Americans who have disabilities. Without question, progress has been made in addressing some of these needs.

Children with disabilities are no longer kept out of the public schools, but instead are increasingly receiving mainstream educations that help to ensure their future. Employers are now required to accommodate workers whose disabilities would have prevented them from taking or retaining jobs in the past. Stores, restaurants, hotels, theaters, and government offices can no longer legally be built without consideration of the accessibility requirements of those with mobility or sensory impairments. And public transportation systems—which had long excluded people who could not walk, climb steps, see, or hear—have become increasingly accessible.

It is equally clear, however, that people with disabilities have a very long way to go before achieving equality, complete integration, and full participation in mainstream society. Americans who have disabilities live in poverty at rates much higher than the rest of the population. More than one-quarter of children with disabilities are poor, and among working-age adults with limited job prospects related to disability, nearly one-third live in poverty. Many people who are limited in work are not eligible to receive government benefits, and for those who do receive them, amounts are often not sufficient to keep their families solvent.

Most people with disabilities do not work or have only part-time, low-wage jobs. For this group, employment—or better employment—is an obvious remedy. A clear majority of people with disabilities who do not have jobs would rather be working. Among this group, a substantial number believe they could handle a job if an appropriate one could be found. But despite the ADA and the proven effectiveness and low cost of most workplace accommodations, people with disabilities continue to face discrimination in hiring, promotion, and on-the-job treatment. And although there is some evidence for increased employment rates among people with more severe disabilities, overall

access to jobs has not improved since the ADA went into force. Employer attitudes must change dramatically before people with disabilities are able to join or re-join the labor force in substantial numbers.

Other barriers also limit employment opportunities. The "human capital"—education, skills, and experience—needed to acquire a job is often lacking. Even when adjusted for the differing age distributions of the populations, disability rates among poorly educated people are twice those among the better educated. Thus, on average, a job-seeker with a disability will be less educated than another applicant without a disability, resulting in a competitive disadvantage. And when a person with a scanty job history attempts to enter the labor force, lack of experience and specific skills can amount to an even more powerful disincentive for the prospective employer.

A major emphasis on job training is clearly needed, as is a longer-term effort to improve the educational levels of adults with disabilities who missed opportunities for schooling in their youth. Greater government spending on education and training today will be more than compensated by future reductions in the disability benefit rolls.

Furthermore, the educational disparity must stop: No child can be allowed to receive an inferior education because of a disability. While such students are no longer routinely abandoned by the educational system (and instead are increasingly likely to be taught in the same classrooms as their peers), architectural and other barriers in many locations greatly limit the ability of children with disabilities to participate in school activities. Unless and until these deficiencies are corrected, some students with disabilities will continue to leave school facing a serious disadvantage when applying for a job and will end up living in poverty.

Physical barriers not only prevent schoolchildren from attending classes, but also greatly limit the independence of many adults with disabilities, preventing them from taking jobs, going shopping, seeing a movie, eating out, or staying at a hotel. Communications barriers, such as a lack of Braille signs in an office building or visible fire alarms in a hotel, can be just as damaging. Many businesses have taken significant steps to remove such barriers, often at modest cost, but others do so only after they are taken to court. Again, attitudes must change, and greater awareness of the importance and economic advantages of accessibility must be fostered among business owners and managers.

Some businesses may cry poverty when asked to remove architectural barriers, but there is no excuse for new construction to be designed and built without accessibility in mind, a process that adds only a tiny fraction to the cost of the building. Yet there have been many instances of facilities designed for public use receiving approval for construction and being built without the essential accessibility features required by law. Increased vigilance, better training for architects, and more resources for enforcement are needed to prevent new obstacles from continually being erected in the path of people with disabilities striving for independence.

Private homes are subject to much more lenient requirements: Only certain units in new, multi-family housing must be made accessible—or rather, must be constructed so that future accessibility can be achieved without major renovation. As a result, the present dearth of accessible housing is likely to

Photo: Shirley Nakao

continue into the future, with only a tiny proportion of U.S. homes having any accessibility features whatsoever. Too many families will therefore continue to be forced to move when disability occurs in their midst, or worse, to expel into an institution the member who develops a disability, when a more livable home environment might have sufficed. Only by requiring that more housing be built under accessibility guidelines, and by providing financial assistance to families who want to make their homes more accessible, can these costly, traumatic events be avoided.

Transportation can either aid or hinder independence. While increasing numbers of public transit routes can accommodate riders with disabilities, significant practical and attitudinal difficulties persist in many parts of the country. Air travel is more generally seen as problematic: Equal access is neither assumed nor guaranteed by law, and people with disabilities frequently receive second-class treatment. Long distance train service is slowly gaining in accessibility, while intercity buses remain the least accessible means of transportation.

Although social integration for people with disabilities is a major goal both of the disability movement and of national policy, evidence of substantial improvement in that area is hard to come by. Half of the people with disabilities responding to a 1994 poll cited social isolation as a problem in their lives. They reported just the same low rates of participation in social, cultural, religious, and commercial activities as respondents to a similar 1986 poll. People with disabilities socialize with friends, eat out, go to see movies, and so on much less often than the non-disabled

population. They are significantly more likely to live alone than the non-disabled population, despite the generally greater need among those with disabilities for the kinds of practical support that families can provide.

Antithetical to the goals of integration and greater participation in society is the continued segregation of certain segments of the disability community, particularly the elderly and those with mental retardation or developmental disabilities, who are kept shut away in institutions. Elderly people who experience mental and physical disability are being forced, in greater numbers than ever before, to spend the last years of their lives in nursing homes, where they are too often subject to abuse and neglect. And despite significant reductions in the non-elderly institutional population, a sizable number of persons with mental retardation and developmental disabilities still reside in large, state-run institutions, where opportunities for self-determination and participation in society are generally non-existent.

Increased efforts must be made to transfer these persons to smaller, community-based group homes and to support families in keeping elderly and non-elderly members with disabilities at home. Just as importantly, government policies that foster dependence must be changed to encourage independence. Financial support must be offered for personal assistance and other services received at home, not just in a nursing home or other institution.

Overall, it is apparent that the significant civil rights advances made by the disability community have been slow to affect the day-to-day lives of those within the community. Large numbers of people with disabilities continue to live in institutions, an existence that runs counter to every goal of the disability movement. Others live in conditions of poverty, lack of employment, and often inadequate disability benefits. While greater numbers of stores, restaurants, hotels, sidewalks, buses, and trains become accessible every day, these changes do not appear to have translated to measurable increases in societal participation among those with disabilities. And while many employers report great success with workplace accommodation, people with disabilities continue to experience employment discrimination, remaining underemployed and underpaid.

Society cannot change overnight, and it is important not to overlook positive developments, such as the increased mainstream education of children with disabilities, greater access to public accommodations and transportation, positive reactions of many employers to effective accommodations, and greater community residency of people with mental retardation and developmental disabilities. But only if the nascent struggle for disability rights is continued and expanded will these hopeful beginnings bring about substantial improvements in the status of people with disabilities in the foreseeable future.

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What is DRA?

Disability Rights Advocates (DRA) is a non-profit corporation which strives to protect the civil and human rights of people with disabilities throughout the United States and the world. DRA is run by people with disabilities for people with disabilities. DRA works to end discrimination in access to public accommodations, employment, transportation, education, and housing. DRA's mission is to ensure that people with disabilities will no longer be treated as second class citizens. DRA serves all disabilities, physical, mental, and emotional, and focuses on systemic problems rather than individual cases. DRA has made it a priority to protect those who are the most under represented, such as disabled children, people with sensory disabilities, and those who have been recent victims of vicious stereotypes such as people with depression, learning disabilities and other hidden disabilities.

Headquartered in the San Francisco Bay Area, DRA has also established an affiliate office in Budapest, Hungary and reaches out to provide help and technical assistance in cities throughout the United States and Eastern Europe. DRA monitors the implementation of national policy, supports a network of disability organizations, and provides advocacy and litigation where necessary.

DRA has successfully challenged unfair practices by many of the largest and most powerful companies and institutions in the nation. DRA has successfully represented disabled foster care children, wheelchair users of mass transit, deaf patients at hospitals, and disabled children isolated from their classmates. DRA has brought class actions and other high impact litigation to end discrimination by major retailers, hotel, restaurant, and gas station chains, universities, cities and counties, and other powerful entities. The results have improved access and integration for millions of people with disabilities.

DRA is a private non-profit organization supported by tax-deductible grants and individual donations.

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ISBN 0-9662355-0-9